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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1987

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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PART 9

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND ORGANIZATIONS

Printed for the use of the Committee on Appropriations

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1987

WEDNESDAY, APRIL 30, 1986.

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND ORGANIZATIONS

NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS

WITNESSES

HON. JAMES ROOSEVELT, PRESIDENT, NATIONAL COMMITTEE FOR RESEARCH

DR. STANLEY VAN DEN NOORT, CHAIRMAN, NATIONAL COMMITTEE FOR RESEARCH, UNIVERSITY OF CALIFORNIA DEPARTMENT OF NEUROLOGY, IRVINE, CA

DR. WILBUR J. GOULD, MEMBER OF THE BOARD, NATIONAL COMMITTEE FOR RESEARCH

ROBERT WHITE, IRISH TENOR

Mr. **Natcher**. Our first witnesses this morning will be a panel to discuss the National Committee for research in neurological and communicative disorders. We have before the committee our friend and former colleague in the House, James Roosevelt of California; and Mr. Roosevelt, you and your group come up and have a seat at the table, and we are delighted to have you before the committee.

You know, I think I should say this on the record, I served with Jimmy Roosevelt in the House every day he was here, and every member of the House, on both sides, liked him. That is the best recommendation I could give you, and we are delighted to have you before the committee.

First, tell us who you have with you and how you will proceed.

Mr. **Conte**. Before you do that, Mr. Chairman, I want to concur with what you said. I served with Jimmy, too. I go back even further than that. I was in Samoa when he was in the 3rd Marines, and I almost jumped ship to go with him. He was not only a great Congressman, he was a great member of the Marine Corps.

Mr. **Natcher**. Go right ahead, Mr. Roosevelt.

Mr. **Roosevelt**. Thank you very much, Mr. Chairman.

Mr. Conte, may I express my appreciation to you? All Marines are equal, so all I can say is, Mr. Chairman, as I said, it is always like being rejuvenated to come back and be with you.

I have with me a number of witnesses who would like to be heard briefly. I have Dr. van den Noort, who you met last year, and Dr. Jim Gould, who is well-known in this area; and we also have with us a gentleman who—I really don't know whether he is going to do all of his act or not, but Mr. Robert White. You may have heard him on occasion here in Washington. He has a beautiful tenor voice, and if he doesn't sing for you today, get him to sing for you some other time.

Mr. Chairman, once again, it is my distinct pleasure and honor to appear before you today on behalf of the National Committee for Research in Neurological and Communicative Disorders, of which I am President.

As many of you know, I accepted this assignment because of the devastating impact that neurological diseases and disorders had on our society. Since I have been associated with NCR, I have learned that this field of biomedical research offers some of the most promising results that are calculated to significantly reduce the extreme economic burden that these diseases place on all of us.

I would be less than candid if I sat here and requested that you appropriate enough funds to support all good neurological and communicative disorders research in light of the Federal deficit situation.

Having sat in your seats for many years, I am fully aware of the pressures currently being applied to you.

However, I think it would be a financial error to in any way back away from the commitment that this committee has made to supporting biomedical research in neurological and communicative sciences.

If you interrupt, you lose much of what has been going on before.

I would like at this time to introduce to you my good friend and colleague, Dr. Stanley van den Noort, who is Professor of Neurology at the University of California and Chairman of the National Committee for Research. Dr. van den Noort will explain the urgent need for continued adequate funding for NINCDS-supported research.

May I introduce Dr. van den Noort?

Mr. NATCHER. We we will be pleased to hear from you, Doctor.

Dr. VAN DEN NOORT. Mr. Chairman and members of this distinguished committee, it is again an honor for me to appear before you on behalf of the National Committee for Research. This committee has demonstrated its awareness of the importance of funding neurological research in a most graphic manner, by significantly increasing appropriations for NINCDS for the past three fiscal years. This momentum has created gratitude and support from the neuroscientific community.

However, the Gramm-Rudman-Hollings legislation, coupled with Administration efforts to rescind some of the funds you appropriated for fiscal year 1986, have resulted in a state of real concern.

I am here today to urge you to continue to withstand even greater pressure to cut biomedical research. As Mr. Roosevelt has said so well, we cannot continue to retard progress in our efforts to find the cause and cures for some of our most dread and disabling diseases.

Under the current proposals, including a 4.3-percent across-the-board reduction and Gramm-Rudman-Hollings reductions, the Administration is asking for a funding level for NINCDS of only

$399,351,000. This is down from your appropriations of $433,462,000. This cannot happen without serious and irreversible results.

I am told that NINCDS will be funding only 20 percent of all approved grant applications. That means that more than three-fourths of all approved applications will go unfunded. This, in an area of research offering the most promise, is very depressing, and particularly depressing for young investigators who may leave the field and not be there when we need them in future years.

Your distinguished colleague, Mr. Conte, had the foresight and wisdom to introduce to the House of Representatives a resolution that declares the decade beginning in 1986 and ending in 1996 as the Decade of the Brain.

This resolution calls attention to the entire Congress, and, if you will, the Nation, that this area of discovery is in need of priority attention.

The brain is the most important organ of the body. When the brain is dead, we give the organs to people with a functioning brain. The brain is hard to study; its exquisitely complex architecture is locked in a bony box which receives input from the several senses and directs action responses in expression, speech, posture and movement.

The sciences for study of the brain have lagged far behind research in other organs and diseases. One cannot easily sample the brain as one can with a sample of blood or biopsy a tumor, and the architecture of the brain is such that samples may not come from the part at fault.

Over the last several decades, we have made remarkable progress in our ability to understand how the brain and its connections function in animals, and we have also seen a true revolution in our ability to image the human brain in ever-greater detail with less and less pain and risk.

Despite this, our treatment for most brain diseases has not changed very much in 30 years.

In most fields of medical research, we have problems with disease which need basic medical and biological research to begin to approach rational treatment. With the astounding advances in recent basic neuroscience we are in the unusual position of having great knowledge but relatively less effort in the application of this knowledge to disease.

The analogy would be the folly of giving Professor Goddard funding for a moon shot in 1937 and the greater folly of failing to explore space with the knowledge we now have.

The toll of brain disease is greatly underestimated. Mental retardation, learning and attention disorders, deafness, epilepsy, cerebral palsy, brain and spinal cord injury from trauma, drowning, drugs, stroke, Alzheimer's disease, Parkinson's disease; these are all well-known.

Then there are the many more rare but tragic disorders: Multiple sclerosis, myastenia gravis, amyotrophic lateral sclerosis, which took our dear Senator Javits away this year; muscular dystrophy, Huntington's chorea, which took Woody Guthrie several years ago; Down's syndrome, and hundreds of others.

Collectively, these diseases exact a toll on life, quality of life, and the American economy which exceeds any other set of diseases particularly in terms of enormous social costs due to chronic illness.

Several years ago, a Congressionally authorized study recommended a doubling of our investment in the National Institute of Neurological and Communicative Disorders and Stroke. I applaud that study, but recognize that constraints on the current budget require that this be seen as a longer-term goal.

NCR's Citizen Budget Committee met in February to consider its recommendations to your committee. We debated at length the need to show restraint in our request to you in the light of the above factors.

As a result of those deliberations, the National Committee for Research in Neurological and Communicative Disorders recommends that this committee appropriate funds sufficient to fund 40 percent of approved grants by the NINCDS. This funding level would require appropriations of $533,646,000 for fiscal year 1987.

Please be assured that we are mindful of the fiscal constraints placed upon each of you individually and collectively. However, we have an obligation to the neurological and communicative science communities to urge you to sustain the momentum that exists at present.

Thank you, Mr. Chairman, and members of the committee.

[The statement of Dr. van den Noort follows:]

NATIONAL COMMITTEE FOR
RESEARCH IN NEUROLOGICAL
AND COMMUNICATIVE DISORDERS

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Statement of

Stanley van den Noort, M.D.

Chairman,

National Committee for Research

in Neurological and Communicative Disorders

and Professor of Neurology

University of California, Irvine

Concerning

The National Institute of Neurological and

Communicative Disorders and Stroke

FY 87 Appropriations

Before the

Appropriations Subcommittee for the

Departments of Labor - Health and Human Services - Education

United States House of Representatives

on behalf of

National Committee for Research

April 30, 1986

A COALITION OF PROFESSIONAL AND VOLUNTARY HEALTH ORGANIZATIONS

Thank you, Mr. Roosevelt.

Mr. Chairman and members of this distinguished Committee, it is again an honor for me to appear before you on behalf of the National Committee for Research. This Committee has demonstrated its awareness of the importance of funding neurological research in a most graphic manner -- by significantly increasing appropriations for NINCDS for the past three fiscal years. This momentum has created a startling interest on the part of young researchers in the neurosciences.

However, the Gramm-Rudman-Hollings legislation, coupled with Administration efforts to rescind some of the funds you appropriated for Fiscal Year 1986, have resulted in a state of real concern in this community. I am here today to urge you to continue to withstand even greater pressure to cut biomedical research. As Mr. Roosevelt has said so well, we cannot continue to retard progress in our efforts to find the cause and cures for some of our most dread and disabling diseases and disorders.

Under the current proposals, including a 4.3% across-the-board reduction and Gramm-Rudman-Hollings reducations, the Administration is asking for a funding level for NINCDS of only $399,351,000. This is down from your appropriations of $433,462,000. This cannot happen without serious and irreversible results.

I am told that NINCDS will be funding only 20% of all approved grant applications. That means that more than three-fourths of all approved applications will go unfunded. This, in an area of research offering the most promise, is depressing.

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Let me give you some examples of the need for this research.

[Give some clinical and research information.]

NCR's Citizen Budget Committee met in February to consider its recommendations to your Committee. We debated at length the need to show restraint in our request to you in the light of the above factors. As a result of those deliberations, the National Committee for Research in Neurological and Communicative Disorders recommends that this Committee appropriate funds sufficient to fund 40% of approved grants by the NINCDS. This funding level would require appropriations of $533,646,000 for Fiscal Year 1987.

Please be assured that we are mindful of the fiscal constraints placed upon each of you individually and collectively. However, we have an obligation to the neurological and communicative science communities to keep the momentum going.

Thank you, Mr. Chairman, and members of the Committee.

Mr. NATCHER. Thank you very much, Dr. van den Noort.

Mr. ROOSEVELT. I would like now to introduce Jim Gould, President of the Voice Foundation, and a member of the Board of the National Committee for Research.

Dr. Gould.

Dr. GOULD. Mr. Chairman, Mr. Conte, members of the distinguished committee, I am highly honored to be here to present one part of the vast material that Dr. van den Noort has covered so beautifully.

My goal is to demonstrate how much communication means to the country in general. It is not only illness, but communication that is the very lifeblood of the economy of the country.

The telephone, improvement of its services, the computer and how it is voice-activated and controlled. All of this comes from voice studies.

We learn how to improve our ability to handle equipment. The very new fighter planes are now voice-activated. In other words, the pilots can't punch in and control data as well as their voice can do in any other way, and as we learn more about vocal quality, we learn more in research about how this can be improved, we then improve our status in all aspects of our life in this country.

It is not only the ill, and this we attend to and work on very much, and our laboratories give us objective measurements that can be used for the future in evaluation of patients, but it is also for the very life and economy of the country and for that, I am making this plea for the funds.

I thank you, Mr. Chairman. I thank you, Mr. Conte. I hope the committee will agree to the support that we have requested.

Mr. NATCHER. Thank you very much.

Mr. Roosevelt.

Mr. ROOSEVELT. Mr. Chairman, I now have the pleasure of introducing to you a young man by the name of Robert White. Robert White is getting to be a very famous American tenor who has made a tremendous hit with audiences in England and Ireland, and building a significant following in the United States in recent years.

And you would be interested, perhaps, Mr. Chairman, in knowing that the RCA Company is planning a June release of his performance of Steven Foster's songs, including "My Old Kentucky Home."

Mr. NATCHER. Mr. White, we will be pleased to hear from you.

Mr. WHITE. It is an honor to be here, of course, and my end of this spectrum of interest is really that direct moment of communication, I think, and as a singer, I am so aware of the most important thing I can do, aside from trying to sing well, is to get some meaning across to people.

I do it mostly with my voice on a song level, and I think that on a very practical level, I have been quite aware over the years, through the Voice Foundation, especially with Dr. Gould, of how their work and the research that goes into what they do to find out how this mechanism works, how it ties in with our brain and our whole body in communion, to bring something of health out of the voice helps us singers in our task, both as performers and as teachers.

I have been able to use many of the insights that I have learned through the Voice Foundation to help not only singers come ahead with their own work, but people that are trying to communicate with their voices that work no longer in a happy way for them, and are not singers.

In conclusion, from my point of view as a singer, my happiest time then is when I get the instrument working, the body working well, and the voice going, to see the effect on people, if it is an old song that might bring back memories, I sing very often for the aged who suffer very much from neurological problems; and where they can be frozen one moment and be far away from you, and if you touch them with a song, the memories that wake up, bring them a kind of youth again.

I don't know if this would be the appropriate place to sing "Smiling Through," to say thank you. Would that be out of order?

Mr. NATCHER. Be very much in order, and we will be pleased to hear from you.

[Musical presentation by Mr. White.]

Mr. NATCHER. Thank you very much. We really enjoyed that. We appreciate it.

Mr. ROOSEVELT. Thank you, Mr. Chairman. I wish to thank you for the opportunity of coming before you and stating our case as clearly as possible.

We tried to entertain you just a little bit, and I am grateful for Mr. White.

Mr. NATCHER. Mr. Roosevelt, we want to thank you and your associates for appearing this morning. This has been a good hearing and a good panel discussion.

We say to, Mr. Conte and Mr. Dwyer and the other members of the subcommittee, and to all of the witnesses who appear, and some of them travel thousands of miles, we appreciate it.

We hear the Department witnesses and when we finish the Department of Labor, the Department of Health and Human Services and the Department of Education, then we have our outside witnesses. I say to all of these witnesses, and so do the other members on the subcommittee, we are concerned about what you have to say to us.

You know, this is our country. It is our money, and we need all the help we can get on this subcommittee. We believe on this subcommittee that this is the most important subcommittee of the 13 that we have on the full Committee on Appropriations. This bill contains the money for health and for the education of our people.

This is where we should spend our money. We should spend more of it.

Jimmy, when you were elected a member of the Committee on Appropriations, we had $71,000,000 for NIH. Now it is $5,500,000,000. It ought to be $10,000,000,000. I say that to you frankly. This is where we should spend our money.

When we take this bill to the Floor, we pass this bill, and they join with us on both sides of the aisle and they help us. Two years ago, we passed this bill in an hour and 35 minutes in the House.

This bill used to go to the House floor and stay two, three, four days, and we established an all-time record one time for the number of roll call votes, you were here Jimmy, John Fogarty was chairman of the subcommittee, and we had 22 roll call votes on this bill.

Now, think about it. We don't have that any more, and that is the way it should be, and we want to thank you again. I say this to you, and all of the other witnesses in this room, your testimony means a lot to us, because as I say, this is an important bill and one that our people are concerned about.

Thank you very much.

Mr. ROOSEVELT. Thank you, Mr. Chairman.

WEDNESDAY, APRIL 30, 1986.

HEALTH AND HUMAN SERVICES

WITNESS

DR. ARTHUR FALEK, EMORY UNIVERSITY SCHOOL OF MEDICINE

Mr. NATCHER. Our next witness is Dr. Arthur Falek. Come around, Doctor, we will be pleased to hear from you at this time. Doctor, we are glad to have you.

Dr. FALEK. Thank you, Mr. Natcher.

I am honored to have this opportunity to report to the Subcommittee on Health of the United States House of Representatives, both as a member of the newly-created combined Huntington's disease family organization and as a psychiatric geneticist working with a large population of patients with Huntington's disease and their families.

My testimony is to emphasize the importance of maintaining current funding requests to support the research activities on Huntington's disease at the National Institutes of Health.

As a scientist involved in several areas of study in human behavior genetics, I have concern about projecting support for funds to investigate one genetic disorder over another.

I do not appear before you as a sponsor of a genetic disease of the month, but rather, as a scientist who sees an important opportunity to use the methodologies developed for Huntington's disease to identify the basis for a large number of genetic disorders.

Of the more than 1,600 currently reported genetically transmitted diseases, approximately one-third have a major effect in the nervous system. This reflects the large proportion of genetic information used in the development and functioning of the brain.

Neuropathologic studies at autopsy in patients with Huntington's disease provide evidence that this disorder depletes the brain of small neurons in particular regions.

The molecular genetic evidence, on the other hand, was derived from the DNA in the chromosomes of different tissues, the white cells of the blood of the fibroblasts of the skin.

This information was first reported by Dr. James Gusella in 1983 at the Huntington's disease Center Without Walls in Boston, who identified a molecular marker on a specific chromosome, chromosome 4, tightly linked to the gene for Huntington's disease.

It is now possible to use the observed molecular genetic patterns in family members to identify not only affected individuals, but, as well, presymptomatic carriers of the gene who will develop this disorder sometime later in their lifetime.

This will provide at-risk family members with presymptomatic information on whether they are free of the gene for Huntington's disease as will be their children and the children's children.

Two-thirds of family members, particularly those in the child-bearing years, desire such information. This approach provides the methodology to search for the gene in the many other inherited disorders where the chromosome location is unknown, and where the direct gene products are unavailable for evaluation and potential therapy.

The ethical issues encumbered in providing definitive information to at-risk individuals prior to any evidence of clinical illness has been an area of continuing discussions by both family members and the research community.

Because of the long, ongoing relationships between members of the scientific community and members of the family organizations, the ethical issues are being directly addressed. There are obvious concerns.

One is whether it is appropriate to provide testing and outcome information to all individuals who request it, including those at-risk individuals who are markedly depressed with a high potential towards self-injury or suicide if the test results indicate that the person is a gene carrier.

For the presymptomatic gene carrier, who will be available to help them? There is at present no treatment or cure for this devastating disease.

Molecular genetic studies with Huntington's disease as well as the procedures we employ in providing information and counseling to members of families with this disease will be the basis for the progression in our advancement with other genetically transmitted disorders where the gene locus is unknown and no treatment or cure is identified.

In particular, Huntington's disease is the prototype for other late onset disorders with evidence of genetic transmission including Alzheimer's disease, familial amyotrophic lateral sclerosis, and stroke due to cardiovascular accidents. Earlier onset psychiatric disorders include schizophrenia and manic-depression.

For Huntington's disease, the identification of a molecular linkage marker to the gene not only raises the immediate potential of a presymptomatic test for at-risk family members, but of eventually isolating the gene.

Once the gene composition is known, it should then be possible to determine its pathophysiology to the clinical disorder.

Huntington's disease, therefore, provides a unique paradigm for investigation of many other genetic disorders and potentially those where the mode of genetic transmission is problematic.

Once methods become available to screen gene products, this may lead to an opportunity for gene therapy. An interesting and currently theoretical question is how to insert the normal functional gene into relevant tissue, where it would act to correct the basic defect.

At present, no gene treatment for any human disease has been achieved, but this is the direction of modern medicine. Since population genetic studies have determined that all of us are carrying at a minimum of seven genes that negatively impact on our health and survival, it is most important from both an economic and health viewpoint that the national government support studies of methods to initially identify and in the long run control or cure the most deleterious of these disorders.

The standard for positive health outcomes is available with Huntington's disease, and I urge your support through a continued level of funding for research investigations in neuropsychiatric disorders indicated by the NCR and the NIMH.

Mr. NATCHER. Thank you very much, Dr. Falek. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Dr. Falek follows:]

STATEMENT OF DR. ARTHUR FALEK

DIRECTOR, HUMAN AND BEHAVIORAL GENETICS RESEARCH LABORATORY
GEORGIA MENTAL HEALTH INSTITUTE

AND

PROFESSOR OF PSYCHIATRY
EMORY UNIVERSITY SCHOOL OF MEDICINE

Huntington's disease is both a neurological and psychiatric disorder. I am honored to have this opportunity to report to the Subcommittee on Labor, Health and Human Services and Education and Related Agencies of the United States House of Representatives both as a member of the Executive Committee of one of the major Huntington's disease family associations (Huntington's Disease Foundation of America) and as a psychiatric geneticist working with a large population of patients with Huntington's disease and their families. My testimony is to emphasize the importance of maintaining current funding requests to support the research activities on Huntington's disease at the National Institutes of Health in particular at the National Institute of Neurological and Communicative Disorders and Stroke and at the National Institute of Mental Health.

As a scientist involved in several areas of study in human behavior genetics, I have concern about projecting support for funds to investigate one genetic disorder over another. I do not appear before you as a sponsor of the genetic disease of the month, but rather as a scientist who sees an important opportunity to develop a conceptual framework founded on an interrelationship of new methodologies that have the potential of identifying the basis for a large number of genetic disorders. My request for your support for the maintenance of funds to study Huntington's disease is that molecular genetic research with this classical, usually late onset, autosomal dominant, neurodegenerative disorder characterized by progressive, involuntary movement and dementia has introduced new strategies that provide initial data on the molecular basis for Huntington's disease as well as new biomedical approaches to investigate the etiology of a vast variety of other genetically focused disorders.

The ages of onset for these disorders occur not only in infancy and early childhood but as well at different time points throughout the human lifespan. While the usual age of onset for Huntington's disease is in the late 30's to early 40's, there are as well juvenile cases with onsets beginning as early as age 4 and late onset cases that can only be detected in individuals in their early 60's. The new methodologies and new understanding about gene control, therefore, also presents an opportunity to investigate the basis for inter-and intra-family variations in ages of onset for Huntington's disease patients as well as for those who develop other genetic disorders throughout the lifespan.

Many of these disorders are manifest predominantly in the nervous system. Of the more than 1,600 currently reported genetically transmitted diseases, approximately one-third have a major effect in the nervous system. This reflects the large proportion of genetic information used in the development and functioning of the brain.

Neuropathologic studies at autopsy in patients with Huntington's disease provide evidence that this disorder depletes the brain of small neurons particularly in the basal ganglion and caudate nucleus regions. The molecular genetic evidence, on the other hand, was derived from the chromosomes in the white cells, the lymphocytes, of the blood. This information was reported by Dr. James Gusella at the Huntington's Disease Center Without Walls at the Massachusetts Institute of Technology and Harvard University and his collaborators in population genetics and neurology who identified a molecular marker on a specific chromosome, chromosome 4, tightly linked to the gene for Huntington's disease.

At the present time molecular marker studies in 16 large unrelated families with Huntington's disease have all shown that the gene for this disorder is located on chromosome 4, and that it is possible to use the observed molecular genetic patterns in family members to identify not only affected individuals but as well presymptomatic carriers of the gene who will develop this disorder sometime in their lifetime. This major advance in molecular genetics was based on a successful methodology to locate the gene for Huntington's disease on a particular chromosome, even though the investigators initially had no knowledge of where that would be. Furthermore, this approach provides an opportunity to search for the gene in the many other inherited disorders where the chromosome map location of the gene is unknown and where the gene products are unavailable for evaluation and potential therapy.

A presymptomatic service program for families with Huntington's disease is not yet offered in the United States because the scientific community wants to assure the reliability of the gene locus by conducting studies in a statistically appropriate number of large, unrelated, informative families. This portion of the research program should be completed shortly. The ethical issues encumbered in providing such definitive information on at risk individuals prior to any evidence of clinical illness has been an area of continuing discussions by both family members and the research community. Because of the long, ongoing relationships between members of the scientific community and members of the family organizations the ethical issues are being directly addressed. There are many obvious concerns.

One example is whether it is appropriate to provide testing and outcome information to all individuals who request it including those at risk individuals who are markedly depressed with a high potential towards self injury or suicide if the test results indicate that the person is a gene carrier. Who will be responsible for the long term care of such individuals? There is at present no treatment or cure for this devastating illness.

Molecular genetic studies with Huntington's disease as well as the procedures we employ in providing information and counseling to members of families with this disease will be the basis for the progression in our advancement with other genetically transmitted disorders where the gene locus is unknown and no treatment or cure is identified. In particular, Huntington's disease is the prototype for other late onset disorders with evidence of genetic transmission including Alzheimer's disease, familial amyotrophic lateral sclerosis, and stroke due to cardiovascular accidents (CVA).

For Huntington's disease the identification of a molecular linkage marker to the gene not only raises the immediate potential of a presymptomatic test for at risk family members but of eventually isolating the gene by utilizing other probes and restriction enzymes to overlap and span longer distances of DNA and `walk' to the gene. Now that the gene for Huntington's disease is located on chromosome 4, in a relatively short time it will be specifically localized by fine mapping procedures. It should then be possible to determine the nuclectide substitution(s) that results in the changed protein product at the basis of this disorder. Knowledge of the altered molecular structure should provide the basis for also determining the pathophysiology of Huntington's disease. The success of molecular genetic methodologies with Huntington's disease is in part due to the fact that its transmission is definitive as a completely penetrant autosomal dominant disorder. It provides a unique paradigm for investigation of many other genetic disorders and potentially those where the mode of transmission is problematic.

As noted by others, once methods become available to screen gene products, the determination of the genomic mutation and the mechanisms of expression responsible for the disease may provide the opportunity for rational gene therapy. An interesting and currently theoretical question is how to insert the normal functional gene into relevant tissue where it would act to correct the basic defect. At present no gene treatment for any human disease has been achieved, but this is the direction of modern medicine. Since population genetic studies have determined that all of us are carrying a minimum of 7 genes that negatively impact on our health and survival, it is most important that the national government support studies of methods to initially identify and in the long run control or cure the impact of the most deleterious of these disorders. The standard for positive health outcomes is available with Huntington's disease, and I urge your support through a continued high level of funding for research investigations with this disorder.

WEDNESDAY, APRIL 30, 1986.

NATIONAL EYE INSTITUTE

WITNESS

DR. BRADLEY STRAATSMA, PROFESSOR AND CHAIRMAN, JULES STEIN EYE INSTITUTE, UNIVERSITY OF CALIFORNIA, LOS ANGELES

Mr. NATCHER. Our next witness is Dr. Bradley Straatsma. We are pleased to have you before the committee, and we will be glad to hear from you.

Dr. STRAATSMA. Thank you, Mr. Chairman.

I am Dr. Bradley Straatsma, the Director of the Jules Stein Eye Institute and Professor and Chairman of the Department of Ophthalmology at the University of California.

It is my privilege to present the Citizens' Committee budget for fiscal year 1987. Vision is man's most highly developed sense, and best attainable vision is important to every American.

Two Gallup polls conducted a decade apart indicated that fear of the loss of vision is second only to fear of cancer among the American people.

This fear is reasonably and appropriately justified, because more than 11,000,000 Americans have a loss of vision. 1,400,000 Americans have a serious vision impairment, and more than 500,000 Americans are blind.

Research has demonstrated that the tragedy of blindness can be decreased and markedly reduced by effective programming and planning for scientific studies.

This Congress took a monumental step in 1968 when it established the National Eye Institute. Since then, this Congress and this committee, in particular, have greatly supported the national research effort to decrease the tragedy of vision loss and blindness.

Since the Institute was founded, the research to prevent vision loss has been guided by a series of national research plans. I served as Chairman of the first committee to develop the national research plan in 1975, and thus can appreciate the major importance of planning and identifying the needs and opportunities establishing priorities and leading to judicious investment.

Research is cost-effective in the vision field. For example, the diabetic retinopathy study at a cost of approximately $10,000,000, resulted in a savings of $454,000,000 per year.

This year, we are able to report another study on the early treatment of diabetic retinopathy a study that costs approximately $4,000,000 a year, and yet results in a savings to the American people of $100,000,000 a year.

Research can be cost-effective in terms of alleviating tragic suffering and in practical economic terms. The Citizens' Committee recommends appropriation of $245,000,000 for the National Eye Institute in fiscal year 1987.

This is the consensus recommendation of the National Advisory Council, Research to Prevent Blindness, the Association for Research On Vision and Ophthalmology, the National Retinitis Pigmentosa Foundation, and the American Academy of Ophthalmologists.

This money is in various program categories: Retina, cornea, cataract, glaucoma, and strabismus. Time does not permit a detailed presentation, but there are major opportunities in each of these areas.

For example, retinal disease, probably the largest cause of blindness in the United States, is being approached about a study dealing with the premature infants of low birth weight who are subject to the retinopathy of prematurity.

A multicenter clinical trial is endeavoring to determine the effectiveness of cryotherapy in decreasing the loss of vision that may occur from this tragic disease early in life.

For the diabetic patients, 10,000,000 or 11,000,000 people in the United States, the National Eye Institute is exploring diabetic retinopathy, and a new study, for the Sorbinil Trial, is for the first time approaching the prevention of diabetic retinopathy effects, and must be combined with other studies such as the early treatment, diabetic retinopathy, study, and the Vitrectomy Surgery Study for other effects of diabetes.

Work is going on on retinitis, which currently affects 80,000 people in the United States. Corneal disease affects 3.5 or more million people in the United States, and causes expenditures of about one-third of every dollar devoted to eye care in this country.

Corneal disease is being approached by studies on herpes simplex virus, designed to prevent the recurrences that cause misery to people with this disorder.

Corneal disease also affects some patients with AIDS. Thus, even this disorder carefully enters the spectrum of research being conducted by investigators at the National Eye Institute. Cataracts, it occurs with increasing frequency among the population greater than 50 years in the United States.

For example, cataract of significant degree is present in about 5 percent of people between 52 and 64 years of age, yet increases to nearly half the population between 65 and 74 years of age.

In the United States, approximately 1,000,000 people have cataract surgery each year. Most obtain an intraocular lens, and fully 90 percent recover visual acuity of 20-40 or better with better spectacle correction following surgery, which enables these individuals to maintain a full and active range of activities.

Glaucoma affects 1,200,000 Americans, 60,000 of whom are blind from this disease. Research in this area is now concerned with the development and testing of new drugs that may make it possible for this disease to be controlled with one or two installations of medicine a day, rather than the more numerous installations that might be otherwise required.

Strabismus is important, because 80,000 Americans undergo surgery for this problem. We are now doing a multicenter clinical trial to determine the improvement that may be obtained by prism adaptation in young children and infants before undergoing strabismus surgery.

A great deal of research in neurobiology is required. Vision is described in the budget request we are submitting for your consideration in these various categories, but actually, vision is an integrated process of awesome complexity.

Every second in each one of us, the eyes and visual system undergo 100,000,000,000 floating point equations to simply transform the two-dimensional image that enters each eye into a three-dimensional reconstruction of the reality around us.

This system can be preserved and protected by appropriate research and a judicious investment. The budget request we have submitted provides for these five areas, for training and for construction of new space that is desperately and urgently needed in the research laboratories for vision throughout the United States.

In summary, vision is precious to every American, and not just vision, but best attainable, best possible vision is of vital importance to each individual.

Research has demonstrated that an investment can be appropriate and judicious because early diagnosis and proper treatment saves the vision for literally thousands of Americans every year.

Research is guided by a national plan that sets forth priorities, creates a clear awareness of opportunities and guides funding.

The Citizens' Committee recommends and earnestly requests your consideration of a budget request of $245,000,000 for the National Eye Institute in 1987. We deeply appreciate the opportunity to prevent this testimony, and would be pleased to respond to any questions you may have.

Mr. NATCHER. Doctor, you have made an excellent statement. We appreciate your appearance before the committee, and we want you to know that we appreciate your coming.

[The statement of Dr. Straatsma follows:]

Statement of

BRADLEY R. STRAATSMA, M.D.

in support of

THE CITIZENS' BUDGET PROPOSAL

for the

NATIONAL EYE INSTITUTE

for Fiscal Year 1987

THE UNITED STATES HOUSE OF REPRESENTATIVES

Labor-HHS-Education Appropriations Subcommittee

Congressman William H. Natcher, Chairman

April 23, 1986

BRADLEY R. STRAATSMA, M.D. is Director of the Jules Stein Eye Institute, Professor and Chairman of the Department of Ophthalmology at the University of California, Los Angeles School of Medicine, and Ophthalmologist-in-Chief of the UCLA Medical Center. As Past President of the American Academy of Ophthalmology and Otolaryngology, Past Chairman of the American Board of Ophthalmology, and Past President of the Association of University Professors of Ophthalmology, Dr. Straatsma has provided leadership in the emergence of ophthalmic research to its present state of intensive productivity. He has been influential in the planning and development of the National Eye Institute and its programs since its establishment, and is currently serving his second four-year appointment as a member of the National Advisory Eye Council. Dr. Straatsma is prominent in the international advancement of clinical and investigative ophthalmology. He is President-Elect of the Pan-American Association of Ophthalmology, has been honored by the ophthalmological societies of ten countries and has delivered more than a dozen distinguished lectures here and abroad. Dr. Straatsma's numerous awards include the Honorary Degree of Doctor of Science, *honoris causa*, from Columbia University, New York. He is the author of more than 300 scientific papers on diseases of the visual system and serves on the editorial boards of major professional publications.

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE:

I am Dr. Bradley Straatsma, Director of the Jules Stein Eye Institute and Professor and Chairman of the Department of Ophthalmology at UCLA School of Medicine in Los Angeles. It is my privilege to present the Citizens' Committee Budget for Fiscal Year 1987 under the auspices of Research to Prevent Blindness (RPB), the world's leading voluntary organization in support of vision research.

Vision is man's most highly developed sense. Sight is important for learning, using tools and devices, moving about, and enjoying human endeavor. For all Americans, best possible eyesight is precious.

Conversely, two separate Gallup surveys conducted a decade apart indicate that the fear of blindness among Americans is second only to fear of cancer. Fears are warranted, because more than 11 million Americans have significant visual impairment, 1.4 million of these have severe loss of vision, and more than half a million Americans are legally blind. The cost of visual impairment and blindness can be measured in terms of human suffering and in a cost to the American people of more than $14 billion a year.

Recognizing the importance of vision as a national health issue, Congress took a monumental step when it established the National Eye Institute in 1968 with instructions to develop and lead the nation's vision research program. Since then, the far-sighted actions of Congress and this Committee have provided the organizational base and financial support for a national research effort that saves eyesight for thousands of Americans each year and is poised on the brink of major, predictable, and cost-effective achievements.

The National Eye Institute has been guided by a series of carefully constructed national Vision Research Plans. I served as Chairman of the Committee that produced the first national Vision Research Plan in 1975 and appreciate the value of research planning in identifying needs and opportunities, establishing priorities, and guiding support. As a consequence, the National Eye Institute and the nation's research community act in concert as a coordinated team.

The current national Vision Research Plan: 1983 - 1987 stemmed from the participation of more than 250 leaders of ophthalmology and visual science in the United States and around the world. The national plan has documented areas in which research has been effective and blinding diseases have been reduced or stopped. Even more important, the national plan has identified areas of current need which can now be approached with existing technology and available scientific manpower. This plan presents the realistic opportunities for scientific advance. With judicious investment, we can reduce the tragedy of blindness and cost-effectively reduce the burden of health care for the people of the United States.

Illustrating cost-effective research, the nationwide Diabetic Retinopathy Study (DRS) established laser photocoagulation as a treatment that reduces by 60% the blindness from proliferative diabetic retinopathy. The DRS cost $10.5 million; the estimated savings, in economic terms, are $454 million per year. Now, in 1986, we can add to this the first reported results of the Early Treatment Diabetic Retinopathy Study (ETDRS). This multicenter clinical trial documented that focal laser treatment can halt or even reverse the sight-impairing macular edema that is often associated with less advanced stages of diabetic retinopathy. The cost of the ongoing ETDRS is $4 million and the savings from this research are calculated at nearly $100 million each year. The laser, an epochal scientific advance, is widely used in communications and industry, but according to its discoverer, Dr. Theodore Maiman, the first practical application of laser technology was the treatment of retinal disease. With prudent investment, we continue to achieve major benefits from laser treatments of the retina and several other parts of the eye.

For Fiscal Year 1987, the Citizens' Committee Budget recommends $245 million to sustain the multifaceted, carefully planned program of eye and visual system research. This Budget represents the consensus of the National Advisory Eye Council and the considered judgment of Research to Prevent Blindness, the Association for Research in Vision and Ophthalmology, and the American Academy of Ophthalmology. It is not an inflated figure but a realistic statement of the resources required to maintain the nation's eminently successful program to preserve the best possible eyesight for Americans.

Further considering this Budget, research supported by the National Eye Institute is categorized in five program areas: retina, cornea, cataract, glaucoma, and strabismus-visual processing.

Retinal diseases prevent over 750,000 Americans from reading ordinary newsprint even with the aid of eyeglasses and are responsible for legal blindness of 200,000 citizens. In newborn infants with low birth weight, the retinopathy of prematurity is being attacked with a multicenter clinical trial to determine the efficacy of cryotherapy in preventing retinal detachment and blindness. For the 10 to 11 million diabetics in this country, diabetic retinal disease is being systematically studied by the prevention-oriented Sorbinil Retinopathy Trial and the therapy-oriented ETDRS and Diabetic Retinopathy Vitrectomy Study. The Sorbinil Retinopathy Trial, culminating nearly a decade of research at the National Eye Institute, is designed to determine whether drugs that inhibit the enzyme aldose reductase can prevent or retard diabetes-associated eye disease and neuropathy.

For the approximately 80,000 Americans with retinitis pigmentosa (RP) and the several hundred thousand people who are in their families or carry the RP genes, there is no effective treatment, and basic science research is needed. In the past year, neurobiological studies of visual cells (photoreceptors) in the retina have elucidated critical steps in the transduction process. This is the critical "firing stage" that occurs between absorption of light by the visual pigments and the generation of an impulse that is transmitted from the visual cell to the next cell in the hierarchy of the visual system. Transduction research is likely to increase our understanding of retinitis pigmentosa and our fundamental concepts of the central nervous system.

Corneal disease or injury affects approximately 3.7 million Americans each year. Often painful as well as sight-impairing, corneal and external eye disease accounts for one third of every dollar spent on eye care in this country. Herpes simplex virus (HSV) infection is the leading cause of corneal blindness. The initial infection usually subsides after treatment, but nearly 25% of those afflicted experience a recurrence or a complication within two years. Research scientists have developed an in vivo experimental system that enables study of the process that permits a latent HSV to become a reactivated infection. This is a major advance in efforts to decrease or prevent recurrent HSV infection of the eye.

The external eye may also be affected in patients with acquired immunodeficiency syndrome (AIDS). Caused by the retrovirus HTLV-III, which is present in an estimated one to 1.5 million Americans, AIDS has been diagnosed in approximately 18,000 Americans to date. AIDS patients may develop Kaposi's sarcoma on the external eye, cotton wool patches in the retina, or sight-destroying chorioretinal inflammation. Basic research on AIDS and therapeutic drug trials to control the chorioretinal inflammation are needed.

Cataract may be present at birth or develop at any age but is increasingly frequent among Americans greater than 50 years of age. For example, cataract causing decrease of vision to 20/30 or less is present in 5% of Americans between 52 and 64 years of age, in 18% of Americans between 65 and 74 years of age, and in 46% between 75 and 85 years of age. Evidencing the extent of cataract-related vision impairment, in 1985 about one million Americans had cataract surgery, usually with an intraocular lens implant, which restored visual acuity to 20/40 or better in nearly 90% of the patients. Moreover, cataract surgery was increasingly performed as an outpatient procedure in the United States with an estimated savings of $500 million each year. Skilled microsurgery, implant quality control, and neodymium-YAG laser technology are among factors that have made cataract surgery increasingly safe and cost-effective for Americans. Cataract research is needed to prevent and retard the progression of lens opacities. Among current studies, investigations supported by NEI are using molecular biology-DNA probes to establish chromosome abnormalities in dominant inherited congenital cataract and precise biochemical analyses to study lens protein changes associated with aging-related cataract. A prominent factor in at least some cases of aging-related cataract appears to be oxidation damage caused by ultraviolet and near-ultraviolet light.

Glaucoma, referring to diseases in which increased pressure in the eye is destructive to vision, is present in 1.2 million Americans, many of whom have a decreased visual field and more than 60,000 of whom are legally blind. Most glaucoma patients can control the disease with self-administered eye drops several times daily. Recent research has shown, however, that a significant percentage of patients do not use the prescribed medication regularly. This emphasizes the need for patient education to enhance compliance.

For glaucoma patients, research has documented the efficacy of new medications that require instillation only one or two times daily and the value of argon laser trabeculoplasty, a procedure that increases aqueous humor outflow. For Fiscal Year 1987 glaucoma research includes studies of aqueous humor formation, epidemiologic risk factors, and topical carbonic anhydrous inhibitors.

Strabismus, amblyopia, and visual processing account for significant disease in a large number of Americans and cause 80,000 people to undergo eye muscle surgery each year. Research supported by NEI has delineated the physiological basis for amblyopia ("lazy eye syndrome") and the "critical period" within which congenital cataract surgery must be carried out to be visually successful.

For strabismus (misaligned eyes) a multicenter clinical trial of presurgical prism adaptation is in progress in an effort to increase the successful outcome of eye muscle surgery. Eye muscle surgery with adjustable sutures is utilized with increasing frequency, and small injections of botulinum A toxin are used to produce specific and often time-limited effects. In Fiscal Year 1987 and thereafter, neurobiological research on neurotransmitters and the molecular development and structure of the oculomotor system are needed.

Although NEI-supported research is categorized in five major program areas, vision stems from the eyes and brain, functioning as an integrated system of awesome complexity. The image focused on the retina is sensed by over a hundred million visual cells (photoreceptors) in each eye, processed in the retina, and transmitted through more than a million fibers in each optic nerve to the centers of vision in the brain. Each second the eyes and brain perform about a hundred billion "floating point logical operations" to change the two-dimensional image formed on the retina of each eye into symbols that encapsulate the solid reality of the original object. For this intricate system, research has documented that early detection and prompt, effective treatment of common vision-threatening eye diseases will preserve sight and prevent blindness for many Americans.

The 1987 Citizens' Budget provides support for the five vision research program areas, for research training, and for the outstanding intramural research program of the NEI. It also addresses the critical need for adequate physical space to support the growing capabilities of vision scientists. Many of our universities and vision research institutes have long since outgrown their limited and often antiquated quarters. Eight years ago Research to Prevent Blindness (RPB) determined that the national need for eye research renovation and construction funds was more than $70 million, an amount hardly comparable to today's costs. The private sector has done its part in generously supporting the construction of eye research centers throughout the country, and the response of the Congress over the past two years has been most welcome and encouraging. However, greater Federal assistance is essential to the growing research effort. The Citizen's Budget therefore includes an urgent request for $10 million for Extramural Laboratory Renovation and Construction -- an expenditure that will be cost-effective in economic terms and in the saving of human sight.

In summary, best attainable vision is precious for every American. Research has shown that early diagnosis and effective treatment of eye disease saves vision each year for thousands of Americans who would otherwise be blind, and research is the only hope for Americans afflicted with diseases for which there is no effective treatment at this time. With commendable initiative, NEI is guided by a detailed and realistic national Vision Research Plan that identifies research needs and opportunities, establishes priorities, and promotes cost-effective research. Vision research is important to all Americans and increasingly important to the growing number of elderly Americans who are at risk for aging-related eye disease. I earnestly request that this Committee recommend approval of the Citizens' Budget of $245 million for the National Eye Institute for Fiscal Year 1987. Proposed expenditures in each of the categories of eye disease are specified in the Financial Tables appended to my statement.

I deeply appreciate the opportunity to present this testimony and would be pleased to respond to any questions. Thank you.

NATIONAL EYE INSTITUTE
CITIZENS' BUDGET

(Dollars in Thousands)

	Fiscal 1986 Appropriation	FY 1986 President's Revised Request	Fiscal Year 1987 President's Budget Request	Fiscal Year 1987 Citizens' Budget
BY ACTIVITY:				
Grants:				
Research Grants....	$151,793	$140,045	$139,037	$185,373
Extramural research laboratory renovation, construction and instrumentation....	3,300	3,158	0	10,000
Core and center grants.............	6,100	5,838	5,400	8,700
Individual training...........	2,615	2,503	2,388	3,500
Institutional training...........	2,616	2,504	2,388	3,500
Total Grants.......	166,424	154,048	149,213	211,073
Direct Operations:				
Intramural laboratory and clinical research..	14,901	14,210	15,523	16,127
Research and development contracts..........	6,649	6,363	7,215	10,000
Biometry epidemiology and field program......	1,150	1,150	1,200	1,500
Research management and program services...........	5,948	5,591	6,050	6,300
Total Direct Operations.........	28,648	27,314	29,988	33,927
Total NEI Obligations........	195,072	181,362	179,201	245,000

(continued)

NATIONAL EYE INSTITUTE
CITIZENS' BUDGET (CONTINUED)

(Dollars in Thousands)

	Fiscal 1986 Appropriation	FY 1986 President's Revised Request	Fiscal Year 1987 President's Budget Request	Fiscal Year 1987 Citizens' Budget
BY PROGRAM:				
Extramural Research:				
Retinal and Choroidal..........	$77,300	$71,228	$70,689	$95,605
Corneal Diseases...	28,200	26,253	26,149	35,238
Cataract...........	14,254	13,311	13,275	17,867
Glaucoma...........	15,830	14,731	14,684	19,773
Strabismus, Amblyopia, and Visual Processing..	34,189	31,730	31,631	42,590
Extramural Laboratory Renovation, Instrumentation and Construction....	3,300	3,158	0	10,000
Total Extramural Research...........	173,073	160,411	156,428	221,073
Intramural Research:				
Laboratory and Clinical Research, Biometry and Epidemiology.......	16,051	15,360	16,723	17,627
Research Management and Program Services	5,948	5,591	6,050	6,300
Total Intramural...	21,999	20,951	22,773	23,927
Total NEI Obligations	195,072	181,362	179,201	245,000

WEDNESDAY, APRIL 30, 1986.

NINCDS

WITNESS

DR. ROBERT RUBEN, AMERICAN ACADEMY OF OTOLARYNGOLOGY HEAD AND NECK SURGERY

Mr. NATCHER. Our next witness is Dr. Ruben. Come around, Dr. Ruben. It is a pleasure to have you back before the committee.

Dr. RUBEN. Mr. Natcher, Mr. Dwyer, members of the committee, I took a taxi over this morning, and I am continually amazed at the wondrous process we have in this land, that a private citizen may come and address you, offer our ideas, opinions, and our needs in such a pleasant and such a meaningful way. And I thought about this coming on over.

Let me go into my more formal statement.

Today, I have the added privilege of representing the American Academy of Otolaryngology Head and Neck Surgery, which is the largest organization of otolaryngologists and head and neck surgeons in the world, with more than 8,000 active members, including 96 percent of all the Board-certified otolaryngologists.

The American Academy of Otolaryngology Head and Neck Surgery represents the physicians and surgeons who care for the multitude of problems which affect the ear, nose, throat, head and neck. Each year, we conduct more than 45,000,000 office visits and perform over 7,000,000 operative procedures.

One area of disease which is cared for by the otolaryngologists is that of communicative disorders. These communicative disorders affect a person's voice, speech, language, and/or hearing and listening.

The disabilities of communicative disorders manifest themselves as mental retardation, educational depression, economic disadvantage and social isolation. These result in human suffering and profound inhibition of human potential.

These afflictions affect both the young and the old. Today, I will highlight just one area of communicative disorders, hearing loss in the elderly. A recent National Institutes of Health study of the problems of hearing loss in the population between the ages 58 and 89 shows that 83 percent of this group had some degree of hearing loss as measured by means of a conservative index of hearing loss.

As a significant corollary, the investigators found that 15 percent of this elderly population had no hearing loss. These are the two very nicely defined facts, and 80 percent with a hearing loss, 15 percent of the elderly going off scot free, no problem.

These findings are important in developing our strategies for care of the elderly. First, 83 percent of the population with the hearing loss means that we must provide care for most of our elderly and for those reaching elderly states.

Second, and equally important, that 15 percent did not have hearing loss suggests that hearing loss in old age, presbycusis, is not an inevitable consequence of the aging process.

These findings call for the working out of strategies to assess the efficacy of delivery of care to these vast numbers of elderly with hearing loss. Interventions must be developed with the application of engineering and computer technology for the fabrication of prostheses and communication assisted devices.

The source of these programs should be determined both by investigator initiated awards, RO-1s, and by programs initiated from the Institute's request for proposals, RFPs.

There is a pressing demand for clinical trials to evaluate these interventions. Clinical investigators in the field of hearing loss would ordinarily compete with all the other proposals within the National Institute of Neurological and Communicative Disorders and Stroke, and other Institutes.

A certain percentage would receive funding. However, with the proposed decrease of funds for the NIH in general, and the NINCDS in particular, there is a high probability that none of this work will ever be realized.

The reason for this is that the budget cuts are so severe that approximately only 26 percent of investigator-initiated awards will be funded.

The work in clinical trials and applied research must compete with basic science with very limited funds. Basic science will generally achieve higher priority scores than those of clinical trials.

The proposed constriction of funds will prevent excellent and needed clinical research that had earned priority scores of 1.4 from being funded. Excellent science and urgently needed research will not be able to be carried out because of the lack of funding.

The decrease in funds will not only ration scientific and clinical research in health care, but in this and other disciplines will mean the exclusion of whole areas of endeavor. Exclusion will not only affect current research, but will also discourage and prevent a whole generation of young investigators from becoming trained and being able to work in this area.

The same economic exclusions of scientific areas will also adversely affect the area of basic research of hearing impairment. The second finding, that 15 percent of the population had no hearing loss, is a critical observation that should engender a number of investigator-initiated proposals and the requests for proposals to determine what are the significant characteristics of the population without hearing loss.

This is an important question to be answered so that we can learn how to prevent hearing loss in the total elderly population. This will lead to a vast savings in the care of the hearing impaired.

The probability that new projects in this area will be funded by the NINCDS with a 26 percent funding rate, I feel, is at best problematic. The reason is that this would be new research without a past track record, unable to compete with the more dramatic and established research in various areas such as neuronal regeneration, stroke, head injury, et cetera.

Its inability to compete with the very high priority scores which would go to these other areas will, in effect, eliminate this area of research.

The ability to determine why some people do not have hearing loss in old age and to use this knowledge to develop methods to prevent this from happening to many of our citizens will then be lost.

There is an additional factor which has further aggravated the ability to carry out research in hearing impairment within the otorhinolaryngological community. Heretofore a traditional source for development of faculty and research in otorhinolaryngology has been support which has come from the University.

The proposed reductions in the amount of the University overhead will severely curtail University funds which can be used by academic departments for faculty and research development.

Otorhinolaryngological departments are usually small and rarely have the opportunity to develop large programs because of heavy clinical demands.

These clinical demands come from the need of the otorhinolaryngological faculty to provide the care in the large urban University settings which is, in many instances, the only otorhinolaryngological care of the poor, indigent and medicaid populations.

This care is done by departments with inadequate funding, which does not leave either faculty, time nor resources available for the development of basic and clinical research in this and other areas of communicative disorders.

These departments, without the support from the University, will be unable to provide the type of environment needed to carry out the research or to develop the faculty which will be able to compete for grants.

The decreases in funding of the NIH which had been proposed by the Administration will extinguish whole areas of clinical, applied and basic research, whose purpose is to alleviate human sufferings and increase the quality of life of our population.

I, and the American Academy of Otorhinolaryngology, strongly urge you to support the Ad Hoc Group for Medical Research Funding's request for research funding at $6,090,000,000 for the NIH for fiscal year 1987, and the citizen budget request for the National Committee for Research for Neurological Communicative Disorders and Stroke for $553,646,000 for fiscal year 1987 for the NINCDS.

The funding at these levels will allow for useful clinical, applied and basic research within the specific area of communicative disorders and the general area of otorhinolaryngology. Our problems have been well defined and our targets of opportunity are apparent.

What is needed is that resources be mandated to carry out the necessary research to alleviate the suffering and promote the potential of the people of our Nation.

Thank you very much.

Mr. NATCHER. Thank you very much, Dr. Ruben. You have made an excellent statement. We appreciate your appearance before the committee.

WEDNESDAY, APRIL 30, 1986.

NIAID

WITNESS

DR. RICHARD ROSENTHAL, AMERICAN ACADEMY OF ALLERGY AND IMMUNOLOGY

Mr. NATCHER. Our next witness is Dr. Richard Rosenthal. Come around, Doctor, we will be pleased to hear from you.

Dr. ROSENTHAL. Thank you very much, sir.

I am from Johns Hopkins University, and I am testifying on behalf of the Joint Council of Allergy and Immunology. I have a number of points to discuss with regards to appropriations for the National Institutes of Health.

As you know, research and development in health is one of the five main points in today's testimony. Without adequate research, breakthroughs in diagnosis and for the prevention and management of medical illnesses becomes fewer and far between.

Witness the development of vaccines for dreaded diseases like polio, that cripples; tetanus and diphtheria, that kill and cause heart damage respectively; and German measles, that cause abnormal fetal development.

Without research and development, we would still be managing the chronically ill from these diseases in increased numbers, at substantial costs, rather than prevention, which has saved dollars for the government and the taxpayers.

We have been able to benefit from a number of research techniques that now have widespread application. My mother, who is in her mid-eighties and lives in New Jersey, came down to Johns Hopkins for laser surgery, and it was unavailable a number of years ago.

She had a laser procedure done on her eyes, over in a matter of seconds, which saved her a three to five-day hospitalization, pain and anxiety, both for herself and myself.

A few years ago, this procedure did not exist. Witness again the rapid development of a blood test for the AIDS virus. If not for our state of biological readiness, we could never have developed this test so quickly.

It is now being used to protect and make safe our country's blood supply.

In the most recent issue of the AMA News was an article about the AIDS vaccine on the horizon, and this would not be realistic if not for the existing scientific data base, and the capabilities which are already in place.

If not for our existing biomedical community, we would not be in a position to confront this modern plague of AIDS, which was undreamed of only five years ago.

The number of appropriate grants to the NIH must continue to grow at a rate similar to the past two years, when it was increased from 5,000 and 6,000 grants.

We, in the field of allergy, immunology and asthma, would support this level of appropriate grants. However, the program mechanisms of training, clinical trials, intramural research, construction and renovation at the NIH and at various centers for related immune disease programs must be supported as well.

Only then can proper staffing and management of the program be adequately done.

Recent directives and actions by the NIH and OMB to reduce funding across the board seriously impinges upon the individual Institutes to appropriately manage their own programs.

Each Institute knows the priorities which are appropriate to their needs, as have been ascertained by input with advisory consults as established by Congress. New actions to reduce each program and activity within the NIH by 4.3 percent across the board by the Secretary and the OMB contradict the authority of each Institute.

Efficiency by directives to centralize decisions such as across-the-board reductions can be very counterproductive. Such directives increase the levels of paperwork and "lines of checking" for decision-making and control. This can only add to the overall costs of management, which could have been allocated to research.

Under the directives of Gramm-Rudman, the budget is the driving force of policy as opposed to Congressional authorization. One formula for all takes the flexibility out of individual Institute decisions.

We urge you to develop bill language restoring this flexibility to the individual Institutes. Very strong language was used last year in the report, yet OMB, NIH and the Secretary's office completely ignored it.

I want to touch upon training, and the importance of training.

It takes five to seven years of hard work to develop minds that can carry on and develop the ideas of research. Interruption of any phase of this long-term investment will result in decreased output for research and development, with consequent increases in the long-term costs and disease management.

Mixed signals of funding may lead to discouragement and reduction in this resource for future research needs. Without researchers, the discussion for funds in the NIH is irrelevant.

Equipment and instrumentation is yet another issue. The need for proper equipment and instrumentation is the second most critical part for research. This is the most costly, but the technology explosion has allowed innovative research ideas to be implemented.

One not only deals with macrobiology of the body or the organ system, but in research today the answers seem to be an intricate working of the cell.

Obviously, proper equipment speeds up the research and produces results that lowers the cost of medical care. It allows a better understanding of how cells work, how medicines help and decreases misunderstandings regarding the disease.

Lastly, construction and renovation. Construction and renovation is an awesome topic, because of the need which is estimated at $2,000,000,000 to $4,000,000,000. Some points are evident, however:

It is going to get less expensive later by not doing anything now. Many of our facilities which were built in the 1950s and 1960s are slowing down our research progress as much as not having the equipment or trainees.

Funding for this program is usually ignored because of the authority question.

We would suggest that you do have the authorization under section 301 of the Public Health Service Act. We recommend starting a program under section 301 of approximately $200,000,000 in fiscal year 1987 to begin taking care of our research construction needs.

Lastly, the need for education.

Funding for public education and outreach programs cannot be ignored. An important step in prevention is to recognize the problem and learn the prevention techniques. A good example of this is tuberculosis control, where no other mechanism exists, except for environmental control and treatment of positive cases.

Another good example is AIDS, where educating the public substantially lowered the infectious rate. The third example is the asthma care training management program, where the most vulnerable are the children, who lose more school days because of allergies and asthma, than any other chronic illness.

In this educational program, the rate of reduction of illness days, hospitalization and emergency room visits is already an established fact. Funding for public information groups saves in the long run to markedly decrease the costs of health management.

We urge you to continue a strong medical research program and not fall to the whims of short-term budget problems. At a time when we are spending $400,000,000,000 annually in this country on health costs, $6,000,000,000 to $7,000,000,000 for research is not at all out of line.

The Ad Hoc Group for Research should certainly be viewed as a minimum. In fact, we today are spending less on medical research as a percentage of health care costs than we were in 1977. It is 1.5 percent now.

I can't think of another area where the taxpayers get so much bang for the buck. It is a tribute to the caliber of the scientists and physicians in this country that they have been able to be so orderly and efficient.

We breed scholarship and above all progressional accountability. Scientists to be be awarded grants must publish advancements in knowledge in peer review journals and they are constantly on trial by their peers.

If we are ever to get a handle on health care costs, we must develop education and prevention and effective treatment programs, and the only way to do that is through a continued medical research.

I appreciate having the opportunity to address this panel.

Mr. NATCHER. Thank you very much, Dr. Rosenthal. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Dr. Rosenthal follows:]

TESTIMONY
ON BEHALF OF THE
JOINT COUNCIL OF ALLERGY AND IMMUNOLOGY
BEFORE
THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES SUBCOMMITTEE
PRESENTED BY
RICHARD R. ROSENTHAL
APRIL 30, 1986

MEMBERS OF THE COMMITTEE

I have six points to discuss with you in regards to the Appropriations for the National Institute of Health.

1. Balance of Research

Research and development in health is one of the five main points in today's testimony. Without adequate research, breakthroughs in diagnosis and the prevention and management of medical illnesses becomes fewer and far between. Witness the development of vaccines for dreaded diseases like polio, that cripples; tetanus and diptheria, that kill and cause heart damage respectively; and german measles, that cause abnormal fetal development. Without research and development, we would still be managing the chronically ill from these diseases in increased numbers, at substantial costs, rather than prevention, which has saved dollars for the government and the tax payers. Witness, if you will, the development of the laser beam that has changed laboratory procedures for measuring serum proteins from days to minutes. Once again, research and development reduced the long-term costs of diagnosing these diseases.

The numbers of the appropriate grants for the NIH must continue to grow at least similar to the rate in our past three years, where it has increased from 5,000 to 6,000 grants. We, in the field of allergy, immunology and asthma would support this level of appropriate grants. However, the program mechanisms of training, clinical trials, intramural research, construction and renovation at the NIH and at various centers for related immune disease programs (CIRID) must be supported as well. Only then, can proper staffing and management of the program be adequately done.

Point #2

Recent directors and actions by the NIH (Secretary) and OMB to reduce funding across the board seriously impinges upon the individual institutes to appropriately manage their own programs.

Each institute knows the priorities which they need and these were ascertained by input with advisory consults established by Congress. New actions of the Secretary and OMB contradict the authority of each institute. Efficiency by directives to centralize decisions such as across the board reductions can be very counter-productive. Directives also increase the levels of paperwork and "lines of checking" for decision making and control. This can only add to the overall costs of management, which should be allocated to research.

In tight budgets, people in consults should decide the priorities, and not one formula for all, which takes the flexibilty out of individual institute decisions.

We urge you to develop bill language, restoring this flexibility to the individual institutes. Very strong language was used last year, yet OMB, NIH and the Secretary's office completely ignored it.

Point #3 - Training

It takes five to seven years of hard work to develop minds that can carry on and develop the ideas of research. Interruption of any phase of this long-term investment will result in decreased output for research and development, with consequent increases in the long-term costs of disease management. Mixed signals of funding may lead to discouragement and reduction in this resource for future research needs. Without researchers, the discussion for funds in the NIH is irrelevant.

Point #4 - Equipment and Instrumentation

The need for proper equipment and instrumentation is the second most critical part for research. This is the most costly, but the technology explosions allow the research ideas to be possible. One not only deals with macrobiology of the body or the organ system, but in research today the answers seem to be an intricate working of the cell for the mirotubular structures that produce the energy systems to the cell walls that make immunity the basis of understanding many medical diseases. Obviously, proper equipment speeds up the research and produces results that lowers the cost of medical care. It allows a better understanding of how cells work, how medicines help and decreases misunderstandings regarding the disease entity.

Point #5 - Construction and Renovation

Construction and renovation is a scary topic simply because of the need which is estimated at $2 - $4 billion. Some points are evident however:

- --It is not going to get any cheaper by not doing anything.
- --Many of our facilities which were built in the 1950's and 1960's are slowing down our research progress as much as not having the equipment or trainees.
- --Funding for this program is usually ignored by the authority question.

We would suggest that you do have the authorization under section 301. If not there, one can be created. We would recommend a program of $200 million in fiscal 1987 to get the process started. We would also recommend that there be an equal match of Federal to private dollars as a requirement for any project to prove the intent and need of those applying. This formula would mean that the $200 million federal investment would equate to $400 million, not to mention the tremendous numbers of both short and long-term jobs created.

These last few points raise the larger issue of our research infrastructure. What roads, ditches, dams, airports and bridges are to this country--grants, contracts, a strong intra-mural program at NIH, patient education, equipment and building are to the fabric of medical research. Thus balance and flexibilty are necessary.

Our investment in this area pays for itself many times over.

Point #6 - Education

Funding for public education and outreach programs cannot be ignored. An important step in prevention is to recognize the problem and learn the prevention techniques. A good example of this is tuberculosis control, where no other mechanism exists, except for environmental control and treatment of positive cases. Another good example is AIDS, where educating the public has substantially lowered the infectious rate. The third example is the asthma care training management program, where the most vulnerable are the children, who lose more school days because of allergies and asthma, than any other chronic illness. In this educational program, the rate of reduction of illness days, hospitalization and emergency room visits is already an established fact. Funding for the public information groups saves in the long run to markedly decrease the costs of health management.

We urge you to continue a strong medical research program and not fall to the whims of short term budget problems. At at time when we are spending $400 billion annually in this country on health costs, $6 to $7 billion for research is not at all out of line. The Ad Hoc's Group for Research should certainly be viewed as a minimum. In fact, we today are spending less on medical research as a percentage of Health care costs than we were in 1977. If we are to ever get a handle on these costs, we must develop education, prevention and effective treatment programs. The only way to do that is through medical research.

WEDNESDAY, APRIL 30, 1986.

LUPUS RESEARCH

WITNESS

THEODORE GOTTHELF, THE LUPUS RESEARCH INSTITUTE

Mr. NATCHER. Our next witness is Mr. Theodore Gotthelf. We are glad to have you before the committee and we will be pleased to hear from you.

Mr. GOTTHELF. Good morning, Mr. Chairman. I am Chairman of the Board, Terri Gotthelf Lupus Research Institute.

I would like to request my full statement be put into the record so I can give a brief summary of it today.

Before doing so, I would like to congratulate and acknowledge the excellent work of yourself and your committee in supporting medical research.

The Terri Gotthelf Lupus Research Institute was formed to conduct research which would lead to the cause and the cure of the disease itself, a disease that is not readily identifiable in and among the medical professional groups.

I have an alternate lifestyle which is being a businessman and supporting research along the lines that I feel can be done by conjointly having efforts between Government and private industry to support research, therefore, making the burden sort of a divided interest.

I am the general manager of the Over-the-Counter Consumer Products Division of Boehringer Ingelheim, one of the world's largest drug companies. I am also the father of a victim of lupus and my daughter and myself before her death established this institute.

In my professional career, I have been instrumental in developing many drugs that led to the cure, prevention and symptomatic relief of diseases. The goal of the institute for the elimination of the disease would be quite simple.

The stimulation of public and private lupus research, acting as a focal point for the principal lupus researchers in the country and disseminating information on their subjects, their products and results to others so that they can again conjointly be able to understand the extent of the disease and its potential cure and, most importantly, the support of young scientists, as we do, to encourage them to choose the field of lupus research as a lifetime career.

The disease itself is fully outlined in my report and it is sort of a hideous type of situation because it attacks the body in a way that no other disease does. Being a bioimmune disease, it manifests itself in a way that is not identifiable at the present time.

It is distinct in its activity in the body from all other diseases. The heartbreaking thing is that it really attacks young women of child-bearing age and the disease is prevalent among women 90 percent of the time. It is frequently misdiagnosed and there is little focus on lupus itself as a distinct disease.

Congress recognized this problem and required better coordination of the research efforts and was supported by several of the institutes in the NIH. We need to make sure that we don't lose sight of the importance of conquering this pervasive and destructive disease by focusing too much of our attention on proposing and defending budgets.

We should make sure that there is a workable strategy for conquering lupus and that we use the resources as effectively as possible. As you know, there is a tremendous amount of work being done in the private sector on the immune system.

A very substantial amount of money is being spent in that area and certainly Dr. Tony Fouci's work on AIDS has brought to life the way in which industry and the Government can conjointly utilize that effort and monies in a program which could bring about the solution to a particular drug product that could be used in the AIDS complex disease.

There are other related drugs and diseases that could be used amongst those victims. We would like to focus on a basic strategy.

I respectfully request that report language be inserted in the record supporting efforts to develop a research agenda for lupus, continue the effort supported by this committee to improve the coordination of lupus research among the varied Federal agencies and increase cooperative efforts between the public and private sectors to improve the effectiveness of research in lupus and related immune deficiency diseases.

I thank you for giving me this time to speak before the committee.

Mr. NATCHER. Thank you, Mr. Gotthelf. We appreciate your testimony. You have given us an excellent statement.

[The statement of Mr. Gotthelf follows:]

TESTIMONY
ON BEHALF OF THE
TERRI GOTTHELF LUPUS RESEARCH INSTITUTE
FUNDING FOR FISCAL YEAR 1987
BEFORE
THE LABOR, HEALTH AND HUMAN SERVICES SUBCOMMITTEE
OF THE
HOUSE COMMITTEE ON APPROPRIATIONS
PRESENTED BY
THEODORE J. GOTTHELF
CHAIRMAN OF THE BOARD

APRIL 30, 1986

STATEMENT OF THEODORE J. GOTTHELF, CHAIRMAN OF THE BOARD

TERRI GOTTHELF LUPUS RESEARCH INSTITUTE

I am here today representing the Terri Gotthelf Lupus Research Institute, a national organization devoted to supporting and conducting research which will lead to finding the cause and cure for lupus. My other positions and interests may make my statement a little different from those of other organizations. Professionally, I am General Manager of OTC/Proprietary Drugs for Boehringer Ingelheim, the eighth largest drug company in the world. I am also the father of a daughter who was a victim of lupus. That is why I established the Institute. In my professional career, I have seen many drugs developed which led to the cure, prevention, or symptomatic relief of disease. The goal of the Institute is to do the same for lupus by:

- o stimulating public and private lupus research;
- o acting as a focal point for the principal lupus researchers in this country;
- o disseminating information on their projects and results to others; and
- o insuring that young scientists are encouraged to choose the field of lupus research as a lifetime career.

Several Institutes within the National Institutes of Health support research which will lead to finding the contributing factors causing lupus and how to prevent and cure the disease.

The exact amount of research grant dollars is difficult to establish because so much of the investigative work is related to other diseases. There is no single source of information on lupus in the federal government.

Rapid strides are now being made in understanding the diverse involvement of the immune system. We must not reduce the current level of support and lose the momentum which has been started. I also recognize that we must use our resources wisely. My testimony will reflect these dual concerns by:

- highlighting some of the progress which has been made in lowering the mortality rate associated with the disease;
- emphasizing the importance of federal support for research because of the relationship of lupus to other immunodeficient diseases;
- suggesting how the effectiveness of the federal investment in lupus research can be improved; and
- proposing some initiatives for achieving greater cooperation between the public and private sector.

MISSION OF THE INSTITUTE

Before beginning these points, let me describe the mission of the Institute and why it was founded. Until the Institute was established, there was no single center focusing entirely on lupus research. The Institute is dedicated to supporting, coordinating and conducting clinical and experimental research in the field of lupus and related diseases. It is a new organization but we have been able to enlist the support of the outstanding scientists in lupus and immunologic research in the country. Through our advisors we are developing a strategy for influencing to a greater degree the direction of research in the etiology, diagnosis, and treatment of lupus.

The Institute was established because there was no other single focus for lupus research and, therefore, there was little coordination of the ongoing efforts. It serves as the center for carrying out a series of activities to document and share the results of current research efforts on lupus and related diseases; assemble an inventory of research findings; and publish information on the disease which can be used by clinicians and scientists, as well as by the public.

PROGRESS ACHIEVED

Systemic lupus erythematosus (SLE) is a spontaneously occurring, multisystem, inflammatory connective tissue disease of unknown etiology. According to available data, there are more than 50,000 new cases diagnosed each year, and the disease affects more than 500,000 people in the United States. That number is grossly understated. Unfortunately, there has been no national incidence or prevelance study so that we know more scientifically the number affected, their characteristics, and most common symptoms.

SLE usually begins in adolescence. Approximately 90 percent of patients are females. The most common clinical manifestations of SLE in decreasing order of frequency are: joint pain and swelling, fever, rash, nephritis, pleurisy, central nervous system involvement, pneumonia, and heart disease. Although SLE affects multiple body systems, the more frequent lesions or conditions that generally determine the course of the disease are found in the kidneys.

Approximately 40 percent of lupus patients have renal involvement, the major cause of end stage renal failure. The overall ten-year survival rate has improved considerable for all lupus patients. In 1955, the average survisorship was 50 percent four years after diagnosis. Now over 95 percent of SLE patients survive five years and over 80 percent survive 15 years. However, those with nephritis have a five year survival of 67 percent. Those who do survive often have disabling complications, an important consideration because most of those affected are young women in their child-bearing years.

There are some interesting observations that can be made about SLE.

- It is one of the oldest diseases known. It is now clear that it is much more common than thought 20 years ago and is recognized as one of the most frequent serious disorders of young women.
- It frequently is misdiagnosed because of its multiple effects on the body and the similarity of the clinical manifestations to those of other diseases; for example, it has often been diagnosed as arthritis and treated as arthritis, incorrectly so. Arthritis is an inflammation of the joints and a less life threatening disease. It does not affect the vital organs, leading to death.

- Clinically, SLE is regarded as the proper type of an immune complex disease in man, one of the new exciting areas of research carried out by the National Institutes of Health and in the private sector.
- Yet we still do not know the cause of lupus, nor how to prevent or cure the disease.

Let me add a final, timely observation. Dr. Tony Fauci, the Director of the National Institute of Allergy and Infectious Diseases, is a lupus scholar as well as one of the leading experts on AIDS. Some of his remarks before the Appropriation Subcommittee just a year ago suggest the importance of lupus research. He stated that: "The study of lupus has probably shed more light on the complexities of immune function and given us more insight into a vast array of diseases than any other single disease directly or indirectly involving the immune system." He went on to say that of importance at this time is the fact that much of what has been derived from studies involving patients with lupus has been used to isolate the profound defect in immunologic function seen in patients with AIDS. Therefore, according to Dr. Fauci, the implications of studies of lupus are far reaching for diseases affecting the immune system and particularly AIDS.

FEDERAL RESEARCH EFFORTS

Research on SLE is supported by several Institutes at NIH. The National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK) and the National Institute of Allergy

and Infectious Diseases (NIAID) are both leaders in terms of the amount of grant support for lupus research performed in medical centers all over the country and in carrying out intramural research on SLE at the NIH Clinical Center.

The most recent report submitted by NIH (dated September 1983) to the House Committee on Appropriations on Lupus Erythematosus Research noted that: "There are few areas of connective tissue disease research that have engendered more interest during the past decade than the study of SLE. In addition to studies in man, excellent experimental models of SLE have been developed in certain inbred strains of New Zealand and American mice...Research in SLE has been very active and, as a result, new concepts of the nature of lupus have been formulated and subjected to critical testing."

Current research funding supports basic research to identify underlying causes of the disease. The clinical research supported by NIH has resulted in a number of new findings related to improved predictors of the outcome of lupus nephritis and the use of cytotoxic drugs to slow the progression of kidney failure. Some of the important research supported by NIH is in the manipulation of the immune system which will have broad implications for other immune disorders. Since the 1983 report, no cumulative analysis of the research results has been completed nor has there been a strategy developed to manage and coordinate the overall research efforts throughout NIH.

IMPROVING THE FEDERAL INVESTMENT IN LUPUS RESEARCH

I come here today as someone who believes that the cause of lupus can be found with a dedicated, managed research effort. I have a personal interest in making sure that this happens. But I am also a businessman who understands that resources are not unlimited. Therefore, I want to propose a few steps that will improve the effectiveness of the research program. None will cost more money. The results, I believe, will save money and lives in the longer term because we will get to the goal sooner.

These steps are based on the activities of the Institute over the past year in analyzing the federal role in lupus research. We have done our homework by learning as much as we can about federal support of lupus research. Let me share with you some of our findings and what I propose as solutions or positive steps forward.

First, we really don't know what is being spent on lupus research and the results of the government expenditures. In its report on the fiscal year 1983 budget for the Department of Health and Human Services, the Committee on Appropriations stated:

> "The Committee is concerned about lupus erythematosus, a chronic inflammatory disease of the connective tissue, ninety percent of whose victims are women--most often black women in their childbearing years. The Committee would like to be kept informed of any positive research findings on the cause and treatment of lupus that may emerge from research

relating to this disease sponsored or conducted by the various Institutes."

The only report issued was in September 1983. No report has been issued since that time.

Second, there is no national strategy or research agenda for lupus which would insure that the various efforts are directed and coordinated. The 1985 NIH authorization bill included a provision that a Lupus Erythematosus Coordinating Committee be established to plan, develop, coordinate, and implement comprehensive federal initiatives in research on the disease. The Committee, composed of the directors of seven institutes within NIH, is to meet at least four times a year until a report is submitted 18 months after enactment of the legislation. As far as I can determine, there has been little progress in meeting the purposes for which the Committee was established.

Third, there is little dissemination of information on ongoing research efforts supported by NIH. There also are few data disseminated on the results of the research which is supported with NIH funding. A substantial period of time elapses from the date that a research grant is submitted, through the review and award stage, the period when the research is conducted and terminating in the submission of final reports and data. The result may be duplication of research efforts because a scientist in one laboratory may not be aware that someone else is engaged in the same research.

My fourth observation in regard to the federal role in lupus research is the lack of active and ongoing cooperation between the public and private sector. There are obstacles, of course. There is a professional reluctance to share findings. We in the private sector often put too much emphasis on our responsibility to our stockholders. This is changing. The private sector has increased their financial investment in research, a positive step in this era of strained public resources. In 1984, pharmaceutical companies spent over $4 billion on research and product development.

IMPROVING THE RETURN ON THE RESEARCH INVESTMENT DOLLARS

In opening this statement, I said that I would suggest how the effectiveness of the federal investment in research could be improved. By maintaining the same level of federal support, we can increase ~~the~~ return on investment by making the research efforts less duplicative and more effective.

First, by developing a research strategy or agenda which would serve as a framework for lupus-related efforts. The agenda would be based on an assessment of the areas which offer the greatest potential for significant results, a determination whether there is ongoing research in that area, and an assignment of the relative priority of the area within the total agenda. In other words, there would be a plan developed by an eminent group of scientists to insure that the resources are used as effectively as possible.

Second, by establishing a process for disseminating information on current and completed research to the broader scientific community. In this way, an idea originating in one university laboratory would be shared with those working in private industry laboratories or at the NIH Clinical Center. Lupus research is too dynamic an area to be dependent on scientists learning results years after they are achieved.

Third, the public and private sectors must develop mechanisms for working more closely together. Research is expensive. The diverse actors in the two sectors should develop clear relationships, sharing knowledge and identifying areas of needed research.

My remarks are not meant to be entirely critical of the federal management of lupus research. Much has been accomplished in combatting this pervasive disease and we must not diminish the level of federal support. However, we need to make sure that the federal dollars are spent as effectively as possible. We in the Institute and in the private sector are willing to work with the federal government in developing a partnership to accomplish this goal.

WEDNESDAY, APRIL 30, 1987.

NIAID

WITNESS

DR. SHELDON M. WOLFF, INFECTIOUS DISEASES SOCIETY OF AMERICA

Mr. NATCHER. Our next witness is Dr. Sheldon M. Wolff.

Dr. WOLFF. Mr. Chairman, members of the committee, my name is Sheldon Wolff. I have for the last nine years been Chairman of the Department of Medicine at Tufts University School of Medicine, and Physician-in-Chief of the New England Medical Center.

My testimony today is presented on behalf of the Infectious Diseases Society of America, an organization of physicians and scientists dedicated to the sharing of knowledge and the fostering of research in the area of infectious diseases.

Mr. Chairman, I would like to take this opportunity to express the IDSA's appreciation to you for your support for the National Institute of Allergy and Infectious Diseases (NIAID). As you well know, the NIAID's mission extends to the prevention and control of infectious and immunologic diseases.

These are the areas of science and medicine that are of overwhelming concern to the American public. Considering that scientists continue to discover that diseases once believed to be largely noncommunicable are in fact spread by viruses, this public concern is well-founded.

For example, even some forms of cancer have been identified as infectious diseases communicable through blood, childbirth or mother's milk. Presently, over 80 percent of the world's 250,000 cases of liver cancer are directly attributable to the hepatitis-B virus.

The AIDS virus continues to menace public health. In fact, the rate of Americans being struck by this devastating disease is now 700 times as high as it was in 1980. It is estimated that the incidence rate of AIDS in the United States is 35 per million.

While this is substantially below the 350 per million incidence rate NIAID researchers found in Zaire, it is clear that we must act quickly to prevent further spread of this fatal disease before we are faced with a ten-fold increase in our incidence rate.

Since medical costs alone for AIDS patients range from $45,000 to $140,000, the investment of dollars in the research it requires to find ways to prevent and combat this dreaded disease will yield enormous real dollar returns and, more importantly, assuage the fears of millions of people that they too will be victimized by the AIDS epidemic.

The NIAID, however, cannot dedicate itself exclusively to the pursuit of cures and treatments for the myriad infections diseases that plague us at home and abroad, if its attention and efforts are constantly bing diverted by myopic administrative and congressional actions, such as: the rigid funding apportionment policies instituted by the Office of Management and Budget; the precipitous across-the-board funding reductions occasioned by the Gramm-Rudman Act; and the Public Health Service's management decision to consolidate all AIDS funding in the Office of the Assistant Secretary for Health.

I would like to discuss briefly each one of these actions and how it has or will impact upon the NIAID's biomedical research effort.

Biomedical research simply cannot flourish in the highly bureaucratic environment that is being created by the OMB. Specifically, the OMB—which, as you well know, appears to have embarked on a vendetta against the NIH—has instituted a rigid funding apportionment policy that leaves NIH Institute Directors with virtually no flexibility to make crucial operational management decisions that can and do enhance the quality and timeliness of the research that is funded.

For example, individual institute directors are virtually precluded by the OMB apportionment policies from moving even a small amount of funds from RO1 research grants to promising new research, irrespective of the need or merit of such a temporary reallocation of funds.

In other words, it has almost become the case that it is the OMB, and not the NIH that dictates the course of the Federal biomedical research effort—and it hardly requires mention that this is a job for which the OMB staff lacks the requisite scientific expertise or outlook.

The 4.3 percent reduction in biomedical research funding occasioned by the March 1 presidential sequestration order—inspired by the Gramm-Rudman Act—adversely impacted upon all the research efforts supported by the NIAID.

Specifically, under the sequestration order, funding for each and every NIAID research grant was cut indiscriminately by 4.3 percent, and the number of individual awards for research trainees reduced from 85 to 69. These Gramm-Rudman across-the-board funding cuts are anathema to a vital and productive research enterprise.

Worse still, however, are the "optimistic" Congressional Budget Office predictions that the next round of sequestration cuts, scheduled to go into effect September 1, will reduce the NIAID's funding by at least an additional 8.4 percent.

This percentage cut would reduce the NIAID's budget by nearly 13 percent below the fiscal year 1986 appropriation level within a span of seven months, virtually emasculating the Institute's research efforts and all but bringing to a halt our progress toward eradicating and controlling the spread of infectious diseases. It is hard for me to believe that the American public, who overwhelmingly supports this nation's biomedical research effort, is in favor of cuts of this magnitude or description.

The Administration has recommended that all AIDS funding be consolidated in the Office of the Assistant Secretary for Health in order to "highlight, plan and coordinate the total level of resources being devoted to this top public health priority." The latter words were directly from the Office of the Assistant Secretary.

While this centralization of funds and planning authority may look good on paper, it is not in the best interest of AIDS research. First, the proposal will strip the NIAID of over $35 million in AIDS new initiative funds and $26 million in base support.

In effect, 17 percent of the NIAID's total budget will be under the direct control of OASH. Second, consolidation of AIDS funds will greatly hamper the ability of the NIAID to plan effectively the course and direction of its AIDS research effort by adding unnecessary layers of bureaucracy to the decisionmaking process.

Admittedly, coordination of the Federal effort against AIDS is desirable. However, centralizing absolutely the control of funding and research strategy under the OASH will effectively thwart the NIAID's long range planning efforts and prevent the Institute from responding quickly to important AIDS research opportunities. Thus, it is not in the best interest of a dynamic and effective research effort.

As if the constraints on research imposed by the OMB, the AIDS funding consolidation plan and the Gramm-Rudman cuts weren't sufficient detriments to the conduct of biomedical research, the budget requested by the Administration for the NIAID for fiscal year 1987 requested by the Administration recommends a seven percent decrease below last year's appropriation and would precipitate a loss of 87 new and competing research grants.

In the judgment of professional scientists, the NIAID could use productively a funding increase of nearly $170 million. Thus, the cuts of $26 million, or 7 percent, below the fiscal year 1986 appropriations level that the Administration has requested is simply unthinkable because of the irreparably damaging effect it would have on the Institute's research programs.

The NIAID must receive a funding increase of at least 11 percent above its fiscal year 1986 appropriation if it is to maintain ongoing research efforts and ensure that real scientific progress is made toward preventing and controlling numerous infectious diseases.

Thank you very much for this opportunity.

Mr. NATCHER. Thank you very much, Mr. Wolff, for your appearance here today. You have given an excellent statement.

WEDNESDAY, APRIL 30, 1986.

LUPUS RESEARCH

WITNESSES

HON. BILL GREEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

DR. ROBERT LAHITA, LUPUS FOUNDATION OF AMERICA

SUSAN GOLICK, LUPUS FOUNDATION OF AMERICA

SUSAN GREENWALD, LUPUS PATIENT

Mr. NATCHER. Our next witness is Dr. Robert Lahita and Mrs. Susan Golick. We will be pleased to hear from you.

I know you have with you our good friend and colleague, Bill Green from New York, one of our good Members of the House. He is one of our members of the Appropriations Committee. Bill, it is a pleasure to have you.

Mr. GREEN. Thank you, Mr. Chairman.

I have no formal introduction, but I did want to let you know the young lady sitting next to me, Susan Greenwald, is the daughter of my administrative assistant. So I have a personal interest in the testimony you are about to hear.

Mr. NATCHER. Go right ahead.

Ms. GOLICK. On behalf of the Lupus Foundation of America, a voluntary health organization representing the one-half million Americans suffering from systemic lupus erythematosus. We welcome the opportunity to address you about issues of vital concern.

We applaud your outstanding support and continued strong commitment over the past years for research into the causes, prevention, treatment and cure of immune system disorders including lupus erythematosus. We have submitted written testimony to this committee with many of our specific concerns and recommendations and since we will not be able to give that testimony in its entirety, Dr. Lahita and I would like to highlight some of the issues.

I am Susan Golick, founder and Director of the SLE Foundation in New York City and a founder and member of the board of directors of the Lupus Foundation of America. I appear before you looking physically fit.

I am a volunteer and have had lupus since 1969. At that time I was put into a wheelchair and told that I had six months to live.

Since then I have been hospitalized a number of times. Systemic lupus erythematosus may be hard to pronounce but it can be even more difficult to live with. On my right, as you heard, is a beautiful young woman, Susan Greenwald.

We both have systemic lupus. We are examples of the vast range of severity of this disease and we are the ones who are well, well enough to be here today. Many could not be here.

They are in the hospital, bed-ridden, on kidney dialysis or in the worse of all worlds, dead. I have buried many friends in the past few years.

I am very fortunate as some of us are. I don't have visible disabilities and yet mine are no less real. There are reasons why lupus should be a special concern to this committee. Lupus discriminates.

The great majority of lupus patients are women, women in their child-bearing years, in college. Women who are anticipating starting a family, women in their prime of life.

There is a new case of lupus diagnosed every 33 minutes and a patient dies every eight-and-three-quarter hours. Our only hope lies with you. If all of us are to live and live truly productive lives, we need your help.

Our lives are directly related to the advances that can be made into the cause and cure of this disease and our hope lies in research.

When we talk about the kinds of funds that are presently needed for biomedical research, it becomes clear that no voluntary or private organization can possibly substitute or effective supplement the essential financial role of the Government.

We are, of course, aware of the extremely difficult decisions involved in the budget making process, but we urge you to consider that there can be no higher priority in this society than human life.

Thank you.

Mr. **Natcher**. Thank you very much. Doctor, we will be pleased to hear from you.

Dr. **Lahita**. Thank you, Mr. Chairman.

It is a delight for me to be here. My name is Robert Lahita. I am an Associate Professor at the Rockefeller University, and a number of the Lupus Foundation Medical Council.

Lupus erythematosus, as you have heard is a common debilitating disease of the immune system. The disease in either its skin form or generalized systemic form affects 500,000, perhaps up to one million people in America. It is largely a disease affecting women, as you have heard, in the child-bearing years and that ratio is approximately nine women to every male, although the ratio has been reported to be as high as 15 women for every male.

That is after puberty. It affects children and the aged, as well as those people in the child-bearing years. The conservative estimate of the incidence of the disease is presently one in 2,000 individuals but in the high risk groups, which happen to be the minorities like the blacks and hispanic population, the incidence can be as high as one in 250.

The symptoms of the disease vary as does the organ or system that the disease chooses to target. Symptoms like fever, joint pains and rash, kidney failure and, as you have heard, death, represent the range of options for the patient with systemic lupus erythematosus. There is also clear evidence that the incidence of this disease might be increasing.

The current modes of therapy for the disease are sometimes worse than the illness at the present time. They largely involve cell poisons and/or steroids like cortisone. The cause and cure of this disease at this time are enigmas but we are certain that continued aggressive research will result in a cure of this disease by the turn of the century or at last a therapy which is free of untoward side effects.

Progress in the research of this disease over the last 15 years has over-shadowed the modest gains of the last 50 years and the evidence indicates that we are at an exponential increase in our learning curve with regard to this dreaded illness. The expected spin-offs from early resolution of this problem could produce dividends such as an increase in significant knowledge of related diseases like multiple sclerosis, Alzheimer's Disease, rheumatoid arthritis, AIDS and a whole variety of blood and kidney disorders.

The gains to date have been manifest in new methods of therapy which include immuno-replacement therapy, hormonal therapy and a variety of modes designed to redirect and control an immune system which has turned against itself. Just as important, at this time are the men and women who dedicate themselves tirelessly to finding clues to this illness.

Further erosion of support for this group could have an irreversible effect on the thrust of medical research in this critical period. As you make your budgetary decisions, Mr. Chairman, and members of the committee, you cannot and we feel indeed must not abandon the patient or the research effort at this crucial time in the history of medical advance.

Placing biomedical research in this disease at the forefront of this society's priorities is not only a practical investment in human resources of the United States, but a humane and responsible decision and it can be achieved with a reaction of the support given to other essential national priorities.

The results we feel can have equally significant effects for all of the human race for eons to come.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much, Dr. Lahita. We want to thank both of you. You have given us excellent statements and I want to say to Susan Greenwald that we are delighted to have you before the committee.

You know, Susan, I have been here for a year or two. The gentleman that sits on your right is one of the able Members of this Congress and we take our bill to the floor he always helps us. You tell your dad I said that. He always helps us and we appreciate it. Thank you very much.

[The statement of Dr. Lahita follows:]

LUPUS FOUNDATION
OF AMERICA, INC.

1717 MASSACHUSETTS AVE N.W. SUITE 203
WASHINGTON, D.C. 20036 (202) 328-4550

Testimony Before

THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH, HUMAN SERVICES, AND EDUCATION

with respect to the

FY 1987 APPROPRIATION FOR THE
NATIONAL INSTITUTES OF HEALTH

List of Witnesses

SUSAN GOLICK, Lupus Patient
Member, Board of Directors
Lupus Foundation of America

ROBERT LAHITA, M.D., Ph.D.
Associate Professor
Rockefeller University, New York
Member, Lupus Foundation
Medical Council

Accompanied by:

SUSAN GREENWALD, Lupus Patient

APRIL 30, 1986
11:00 A.M.

ADMINISTRATIVE SERVICES OFFICE P.O. BOX 12897 ST. LOUIS, MISSOURI, 63141 -1-800-588-0121

LUPUS FOUNDATION
OF AMERICA, INC.

1717 MASSACHUSETTS AVE N.W. SUITE 203
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Statement for the
SUBCOMMITTEES ON LABOR, HHS, AND EDUCATION
COMMITTEES ON APPROPRIATIONS
UNITED STATES SENATE
and
UNITED STATES HOUSE OF REPRESENTATIVES
with respect to the
FY 1987 BUDGET of the
NATIONAL INSTITUTES OF HEALTH

Presented by:

LUPUS FOUNDATION OF AMERICA, INC.

APRIL 30, 1986

ADMINISTRATIVE SERVICES OFFICE P.O. BOX 12897 ST. LOUIS, MISSOURI, 63141 -1-800-588-0121

Statement for the
Subcommittees on Labor, HHS, and Education
Committees on Appropriations
United States Senate
and
United States House of Representatives
with respect to the
FY 1987 Budget of the
National Institutes of Health

Introduction

The Lupus Foundation of America (LFA), a voluntary health organization representing those Americans suffering from Systemic Lupus Erythematosus, welcomes the opportunity to submit a statement on FY 1987 appropriations for the National Institutes of Health. The LFA applauds the outstanding support and strong commitment exerted by Congress over the past several years for research into the causes, prevention, treatment and cure of immune system disorders, including Lupus Erythematosus. It is because of the continued efforts of Congress that NIH research initiatives have borne significant results, bringing us closer to learning about the immune system and the mysterious disease called lupus.

The Board of Directors, officers, and members of the LFA and its 95 affiliate chapters throughout the country recognize the difficulty Congress faces in attempting to balance national priorities and needs at a time of high budget deficits and a legislative mandate to balance the federal budget. But there can be no higher priority to this society than to protect and enhance the health of its citizens. We urge expanded funding for the programs of the National Institutes of Health which support biomedical research on immune system disorders and thus impact on the lives of millions of Americans.

The Special Case of Lupus Erythematosus

Lupus Erythematosus, commonly called lupus or SLE, is a disease of unknown cause, although its existence has been known for well over a century. Lupus strikes an individual's immune system, a complicated network of organs, tissues, cells, and circulating factors in the blood. Normally, the immune system protects individuals from infection by producing antibodies (protein molecules) that can react with foreign substances and lead to their elimination. In autoimmune diseases such as lupus, the body makes large quantities of antibodies that react against the person's own normal tissue. The immune system is overactive in lupus, while in other immune disorders, such as AIDS, this system ceases to function.

There are two main forms of lupus: Discoid Lupus Erythematosus, which involves only the skin and is a relatively mild disease, and Systemic Lupus Erythematosus, which can affect not only the skin, but also the liver, joints, kidneys, heart, lungs, central nervous system, or any other organ. The range of severity runs from mild aches and pains to a very serious disease that can be fatal to those afflicted. It may appear in different forms and with varying degrees of intensity in the same person.

Between 500,000 and 1,000,000 people in the United States are afflicted with systemic lupus, the more severe form, making it more prevalent than leukemia, muscular dystrophy, cerebral palsy, multiple sclerosis, and cystic fibrosis. Recent data suggest that the overall incidence of lupus in the United States is no less than one person in 2,000. More than 16,000 Americans develop lupus each year. Lupus is a prototype of other autoimmune diseases such as thyroiditis, rheumatoid arthritis, Sjogren's syndrome, and certain kinds of anemia. Continued and expanded lupus research can provide important answers to these other disorders of the immune system.

LUPUS DISCRIMINATES! The disease attacks females at an almost nine to one ratio over males. About 1 in 700 women between the ages of 15 and 64 is afflicted. Minority women are disproportionately affected; lupus strikes one adult White woman in 680; one adult Hispanic woman in 410, and one adult Black woman in 245. The onset of lupus most commonly occurs in the childbearing years.

More and more people are being diagnosed as having lupus. It is as yet unclear as to whether the incidence of this disease is rising or if new and more reliable diagnostic procedures account for the numerical increase.

Symptoms and Treatment. Lupus has been called "The Great Impersonator" because of the frequency in which initial episodes are diagnosed as other diseases. In fact, it is not unusual for a diagnosis of lupus to take five years, and in some situations as many as fifteen years! In the meantime, the individual may suffer any number or combination of a variety of symptoms: fatigue; diminished appetite and weight loss; frequent infections; chronic or recurrent low grade fever; abnormal hair loss; pain in the joints or joint swelling; blanching of fingers after exposure to the cold; red skin rash; photosensitivity; and easy bruising.

As long as the cause of lupus remains an enigma, there is no specific and complete treatment. Although a cure is not now possible, control of the disease is. With early recognition and improved treatment, patients with lupus can live longer and less debilitating lives. The current mainstay of treatment is medication. The majority of drugs used to treat lupus suppress the disease process itself, decrease inflammation, alter immune system function, and/or help to maintain function in other body systems. Steroids, the most well known of which is cortisone, are often used to treat lupus patients. A disadvantage is that this is a powerful drug that can cause harmful side effects. Worse than steroids are cell poisons that may have to be used if the patient is unresponsive to other drugs.

How Far Have We Come? Almost all that we know about lupus has been learned in the last 15 years. The importance of the T and B cells in the immune system and the knowledge that these cells function by secreting certain factors was recognized only within the last decade and a half. Medical scientists are now beginning to examine the interactions of the immune system, the endocrine system, and the nervous system. These current investigations may help shed light on the role of the patient's attitude in a number of diseases. New therapeutic approaches are also being introduced or intensively investigated. These include kidney transplants, pulse therapy, combination therapy, plasmapheresis, intravenous cyclophosphamide, use of monoclonal antibodies, immunoreplacement therapy, and development of new hormonal means of therapy. There is no doubt that the rapidly developing knowledge of the immune system and its regulatory mechanisms is leading to an increased understanding of lupus. With continued and expanded research efforts, there is great promise of dramatic and improved changes in the treatment of this disease and related immune system disorders.

Living with Lupus. Where would we be without past, current and anticipated biomedical research? In the words of one lupus patient:

> With lupus...a patient struggles against pain, dizziness, nausea, and fatigue to maintain a relationship with the world on even a minimal level. At work, one lives with the constant fear of possibly losing employment because of poor performance. There is worry about children, husband or wife, death and dying. There is the need to understand the illness, to know why one feels that way, and to find ways to deal with one's plight.

Lupus can result in pain, disability, and sometimes mortality. The cost to the individuals suffering from this disease can be measured in the quality of their lives, their ability to contribute to society, to develop and sustain professional careers, family relationships, and a sense of psychological and physical well-being. Sometimes, life itself is at stake.

There are costs to society, as well. The American economy is effected by lupus and other immune system disorders; public funds are diverted to increased medical care costs, lost wages and productivity, lost taxes, increased social service costs, and increased disability payments. If a cost analysis is applied, it is certainly more economical for this society to use its resources to control and cure disease than to sustain, for an indefinite period, the vast number of dollars spent as a consequence of disease. Placing biomedical research at the forefront of this society's priorities is not only a practical investment in the human resources of the United States, but a humane and responsible decision.

Research advances within the past decade have brought about improved treatment, disease control, and better diagnostic methods; accelerated and targeted research efforts now and in the future will likely ameliorate, prevent and cure diseases. The cuts proposed in the programs of the National Institutes of Health threaten not only to curtail progress, but to bring to a halt the important work now underway. Losing momentum in biomedical research through reduced or even constant funding levels means a serious loss of research opportunity for many years to come, particularly when one considers that new and potential researchers will be dissuaded from entering biomedical work. The consequences of proposed budget cuts will be counted in human lives.

The Public Role

The intramural and extramural research programs and support of the National Institutes of Health account for the major progress achieved in discovering new diagnosis and treatment knowledge about lupus. Two NIH institutes - the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of Arthritis, Diabetes, Digestive and Kidney Disorders (NIADDK) have supported significant lupus research. The initiation in 1985 of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) has brought the hope of even greater emphasis on, and support for, lupus research.

NIADD research on lupus includes studies on the basic biology and chemistry of the immune system and its function in health and diseases. Intramural and extramural scientists are studying underlying immune mechanisms and their regulation; hypersensitivity and inflammation associated with immune reactions; and other suspected causes of lupus, including infectious agents, drug sensitivity, and genetic predisposition. The many physiological systems and body organs involved in lupus have led to significant research avenues by NIADDK, particularly on lupus as a connective tissue disease. NIADDK is also studying the effects of lupus on the kidney, blood vessels, joints and skin.

It is only with the ongoing information resulting from these research studies that new and more effective methods of therapy, prevention and cure can occur. While the Lupus Foundation of America sponsors small grant awards and fellowship programs each year for researchers investigating Lupus Erythematosus, no voluntary or private organization has the mandate, funding capability, or personnel to address the magnitude of the task.

Recommendations

The LFA supports the recommendations of the National Coalition on Immune System Disorders, the Ad Hoc Group for Medical Research, and the Coalition of Organizations Concerned with the Programs of the NIAMSD for a $6.1 billion budget for the NIH. This sum represents a modest increase of about 1.4 percent over the current services budget and allows the basic and clinical research activities initiated under the FY 1986 congressional appropriations to continue, thus insuring the translation of that research and technology into medical practice to the benefit of those afflicted with lupus and other immune system disorders. The continued training of qualified biomedical investigators is also made possible.

The LFA further recommends that:

- The provisions of P.L. 99-158, the Health Research Extension Act of 1985 establishing the National Institute of Arthritis and Muscoloskeletal and Skin Diseases (NIAMS) be implemented at the level of $151,650,000 (as proposed by the Coalition of Organizations Concerned with the Programs of NIAMSD) to maintain research efforts at current services levels and allow for the initiation of new, as well as continuation grants.
- The recommendations of the time-limited Coordinating Committee on Lupus Erythematosus created under P.L. 99-158 to plan, develop, and implement comprehensive Federal initiatives in lupus research be implemented in full, thus creating new and broadened avenues of lupus clinical investigations.

- DHHS, particularly NIH and the Public Health Service, expand efforts to educate the public and health professional community about the nature and consequence of immune system disorders to assist in early diagnosis and treatment.

The Lupus Foundation of America

Until biomedical research solves the mysteries associated with the awesome disease of Lupus Erythematosus, the LFA and its 95 affiliate chapters will continue to assist persons with lupus and their families to ease the emotional, physical, and practical burdens associated with its course and outcome.

The LFA, founded in 1977, seeks to: provide greater public and professional awareness of this disease and its consequences; intensify publicly sponsored research programs and support and initiate new research efforts through a program of grant awards and fellowships; strengthen physician training to aid in prompt diagnosis and improved therapy; and provide information to patients, their families, government, and the concerned public to encourage understanding, support, and medical advances.

The LFA affiliate chapters, located in almost every state and major U.S. city, are frequently staffed by volunteers. Often, local medical advisory boards of concerned and knowledgeable health professionals assist in the work of the chapters. The chapters put on educational programs for patients and the community and produce and distribute literature on the disease. By taking part in chapter activities, patients with lupus have the chance to learn about their illness and how to live with it, and to develop a feeling of satisfaction from helping others with the same problem.

Please help us help. A cure is possible, but public support is essential.

WEDNESDAY, APRIL 30, 1986.

HEALTH ADMINISTRATION AND HEALTH TRAINEESHIPS

WITNESS

DAVID BERGWALL, VICE PRESIDENT, ASSOCIATION OF UNIVERSITY PROGRAMS IN HEALTH ADMINISTRATION

Mr. **NATCHER**. Our next witness is Mr. David Bergwall. Come around. We will be pleased to have you before the committee. You have been with us before and we are glad to have you.

Mr. **BERGWALL**. Thank you, Mr. Chairman, members of the subcommittee.

My name is David Bergwall. I am here on behalf of the Association of University Programs in Health Administration.

I would like to thank you for the opportunity to present testimony in support of two activities funded by this subcommittee: graduate programs in health administration and health administration traineeships.

By way of background, our Association is a 38-year old consortium, consisting of 153 health administration programs in 144 colleges and universities throughout the world, including the University of Kentucky.

The primary objective of our programs is to strengthen and improve the administrative and managerial leadership in the health care delivery system.

For the past several weeks, Mr. Chairman, this subcommittee has heard testimony from Administration witnesses, like Secretary Bowen, who have emphasized the need to constrain rising health care costs. And, of course, we agree with the Secretary.

Over the last 15 years, national health expenditures have risen from $75 billion to more than $400 billion, with projections that in just four years health care costs will top $600 billion. It is now to the point, in fact, that the total cost of health care consumes in this country is 10.6 percent of GNP.

And while costs continue to spiral upward, Mr. Chairman, we continue to see dramatic changes in the patterns of organization and practice.

In our view, Mr. Chairman, all of this serves to underscore the importance of having well-trained administrators available to meet the demands of our health care system. For no matter how simple or how sophisticated we make it, whether practitioners are in oversupply or not, an efficient health care delivery system is dependent upon sound management. Health administrators, after all, have the ultimate responsibility for administering whatever cost containment measures that you and your colleagues may devise. Responsibility also falls to the health administrator to grapple with the day-to-day problems associated with nursing shortages, physician availability, and technology assessment.

Unfortunately, management competence in health services is grossly uneven. The fact of the matter is that, first, two-thirds of the Nation's health care administrators have not received adequate training and education in this field, and second, that the demand for professionally trained administrators—in HMOs, PPOs, home health agencies, and rural hospitals—far exceeds the supply.

What does this mean?

It means that many of the health professionals whose training you have helped support will not be fully productive. It also means that any cost containment system that is implemented will have limited effectiveness.

In short, Mr. Chairman, this country needs an effective health administration education system. Congress recognized this fact and, last year, adopted legislation reauthorizing these programs. Unfortunately, the President's budget seeks to terminate support—evidently without considering the consequences.

Mr. Chairman, health administration programs are the primary source for attracting young people to careers in health management, training them properly, and for upgrading present managers. Under the circumstances, the relatively small Federal investment in these programs which, by the way, is matched by non-federal funds, is well worth it.

While all the evidence points to the need for an expanded effort, we recognize that resources are limited. Our association, therefore, recommends that funding for health administration programs be continued at last year's appropriations level.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much. You have given us an excellent statement. We appreciate your appearance before the committee.

WEDNESDAY, APRIL 30, 1987.

SMOKING AND HEALTH

WITNESSES

ALAN DAVIS, CHAIRMAN, COALITION STEERING COMMITTEE, COALITION ON SMOKING AND HEALTH

REBECCA LANGAGER, LEGISLATIVE REPRESENTATIVE, AMERICAN HEART ASSOCIATION

Mr. NATCHER. Our next witness is Mr. Alan Davis. We are delighted to have you before the committee at this time. Who do you have there with you, Mr. Davis?

Mr. DAVIS. I am pleased to have my associate, Becky Langager, who is our legislative representative.

Mr. NATCHER. We will be pleased to hear from you.

Mr. DAVIS. My name is Alan Davis, and I am Vice President for Government Relations and Science Editor for the American Cancer Society. It is an honor to appear before you again, sir.

I appear before you today as the Chairman of the Steering Committee of the Coalition on Smoking or Health. The Coalition on Smoking or Health was formed by the American Heart Association, the American Lung Association and the American Cancer Society in January of 1982 to bring the health hazards of cigarette smoking more effectively to the attention of legislators and other public officials. We are pleased to appear before your subcommittee today to make our funding recommendations for the Federal Office on Smoking and Health.

My comments are an abbreviation of the longer statement, and I request my longer statement be included in the record of this hearing.

The Office on Smoking and Health is the Federal focal point for all Department of Health and Human Services tobacco and health activities and serves as a national and international clearinghouse for scientific, technical and general public information regarding cigarette smoking and the use of smokeless tobacco.

The functions of the OSH are diverse but generally fall into three categories: collection and dissemination of scientific and technical information; public education; and regulatory activities. Each of these areas is described in detail below.

Cigarette smoking is the number one preventable cause of death and disability in the United States. Smoking causes 80 percent of all lung cancer deaths and is a significant cause of cancer of the larynx, oral cavity, esophagus, bladder and is significantly associated with cancer of the pancreas and kidney. Cigarette smoking is a major risk factor in the development of cardiovascular disease and causes one-third of all heart disease deaths. Smoking is a major cause of emphysema and chronic bronchitis and causes 80 to 90 percent of all deaths due to these diseases in the United States. Over $22 billion annually in heart care costs; $43 billion annually in lost productivity costs; and over $4 billion annually in medicare and medicaid dollars costs can be attributed to smoking. This $69 billion yearly is in addition to the incalculable human toll of pain and suffering which result from the 1,000 deaths per day because of smoking-related causes.

Use of smokeless tobacco products—snuff and chewing tobacco—is also a serious health problem. The National Cancer Institute estimates that six to twelve million Americans use these products. What is most disturbing about this consumption figure is the increase it represents in the number of male teenagers using smokeless tobacco.

The use of smokeless tobacco will lead to a significant increase in oral cancer deaths in this country. In addition to causing oral cancer, smokeless tobacco produces the following additional adverse health effects: decreased taste and smell sensations; staining of and abrasion of tooth surfaces; advanced periodontal destruction and possible tooth loss; soft tissue losses; and significant increases in heart rate and blood pressure.

The public health problems that are encompassed by the OSH mandate are enormous. The Office does not attempt to tackle these problems alone; we in the voluntary health sector take a very active role in educating the public regarding the health hazards of cigarette smoking and the use of smokeless tobacco.

However, we believe that OSH's role as the central coordinator for the entire national and international health community for tobacco education and data collection efforts is crucial. I would like to provide the subcommittee with a detailed description of the many activities of the OSH.

The OSH accomplishes all of its tasks with minimal resources: a current budget of only $3.24 million and 17 staff positions. In addition, no funding has been added to the OSH budget as Congress has given it increased public education and regulatory responsibilities. In fact, OSH lost three staff positions to PHS management functions in 1985 and the Office suffered a $300,000 budget reduction due to the implementation of the Gramm-Rudman cuts and reductions in funds for consulting services this year.

When one takes into account the staggering fact that the tobacco industry spends approximately $2 billion annually on advertising its products it becomes obvious that even the combined resources of the OSH and the voluntary health organizations I represent are not sufficient to counteract the sophisticated advertising techniques employed by the industry to entice individuals to begin or continue smoking.

The President's budget includes $3.47 million, and they receive an increase of eight physicians for the OSH in fiscal year 1987. We do not believe that this level of funding is sufficient for the Office to carry out all of its current and newly-mandated functions. Therefore, we recommend that the Office receive a fiscal year 1987 appropriation of $4.738 million and that they receive an FTE increase of eight positions.

The Coalition on Smoking or Health and its member organizations believe that without them any functions performed by the OSH, the effort to educate the American public and the rest of the world about the health hazards associated with smoking would be far behind where it is today.

I am here today on behalf of the committee to urge the committee to provide funding for this small but effective office. Hundreds of thousands of lives are depending upon it.

Mr. NATCHER. Thank you very much, Mr. Davis. You have given us a good statement and we appreciate your appearance before the committee.

[The information of Mr. Davis follows:]

Coalition on Smoking OR Health
A PUBLIC POLICY PROJECT WITH THE
NATIONAL INTERAGENCY COUNCIL ON SMOKING AND HEALTH
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ASSOCIATE DIRECTOR
Susan L. Arnold
Asbill, Junkin, Myers & Buffone

Statement of the

Coaliton on Smoking OR Health

Presented by

Alan Davis

Chairman, Coalition Steering Committee

on

FISCAL YEAR 1987 APPROPRIATIONS

FOR THE OFFICE ON SMOKING AND HEALTH

before the

HOUSE LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

The Honorable William H. Natcher, Chairman

April 30, 1986

Summary of Recommendation:

Office on Smoking and Health:
$4.738 million and 25 FTE Positions

"CIGARETTE SMOKING IS THE SINGLE MOST PREVENTABLE CAUSE OF DEATH IN THE UNITED STATES"

My name is Alan Davis and I am Vice President for Government Relations and Science Editor for the American Cancer Society. I appear before you today as the Chairman of the Steering Committee of the Coalition on Smoking OR Health. The Coalition on Smoking OR Health was formed by the American Heart Association (AHA), the American Lung Association (ALA) and the American Cancer Society (ACS) in January of 1982 to bring the health hazards of cigarette smoking more effectively to the attention of legislators and other public officials. These three voluntary health organizations are among the oldest and largest organizations of citizen volunteers in our country; together they have a membership of almost five million volunteers. We are pleased to appear before your Subcommittee today to make our funding recommendations for the Federal Office on Smoking and Health (OSH).

The Office on Smoking and Health is the Federal focal point for all Department of Health and Human Services (DHHS) tobacco and health activities and serves as a national and international clearinghouse for scientific, technical and general public information regarding cigarette smoking and the use of smokeless tobacco. It is located within the Office of the Assistant Secretary for Health. The functions of the OSH are diverse but generally fall into three categories: collection and dissemination of scientific and technical information; public education; and regulatory activities. Each of these areas is described in detail below.

Cigarette smoking is the number one preventable cause of death and disability in the United States. Smoking causes 80 percent of all lung cancer deaths and is a significant cause of cancer of the larnyx, oral cavity, esophagus, bladder and is significantly associated with cancer of the pancreas and kidney. Cigarette smoking is a major risk factor in the development of cardiovascular disease and causes one-third of all heart disease deaths. Smoking is a major cause of emphysema and chronic bronchitis and causes 80 - 90 percent of all deaths due to these diseases in the U.S. Over $22 billion annually in health care costs; $43 billion annually in lost productivity costs; and over $4 billion annually in Medicare and

Medicaid dollars costs can be attributed to smoking. This $69 billion yearly is in addition to the incalculable human toll of pain and suffering which result from the 1,000 deaths per day because of smoking-related causes.

Use of smokeless tobacco products -- snuff and chewing tobacco -- is also a serious health problem. The National Cancer Institute estimates that 6 to 12 million Americans use these products. What is most disturbing about this consumption figure is the increase it represents in the number of male teenagers using smokeless tobacco. The use of smokeless tobacco will lead to a significant increase in oral cancer deaths in this country. In addition to causing oral cancer, smokeless tobacco produces the following additional adverse health effects: decreased taste and smell sensations; staining of and abrasion of tooth surfaces; advanced periodontal destruction and possible tooth loss; soft tissue losses; and significant increases in heart rate and blood pressure.

The public health problems that are encompassed by the OSH mandate are enormous. The Office does not attempt to tackle these problems alone; we in the voluntary health sector take a very active role in educating the public regarding the health hazards of cigarette smoking and the use of smokeless tobacco. However, we believe that OSH's role as the central coordinator for the entire national and international health community for tobacco education and data collection efforts is crucial. I would like to provide the Subcommittee with a detailed description of the many activities of the OSH.

Science and Technical Information

The OSH Technical Information Center (TIC) is a vast repository of current research in smoking and health. The TIC regularly disseminates information to over 5,000 researchers and health professionals. The TIC is the world's only international clearinghouse for scientific information on smoking and health.

The major publication of the OSH is the Annual Surgeon General's Report on The Health Consequences of Smoking. This document is recognized throughout the world as the premier publication on current issues in smoking and health research. The next issue of the Surgeon General's report, due out in November, 1986, will focus on the issue of involuntary smoking and its impact on the health of nonsmokers. The topic for the 1987 Surgeon General's Report is the benefits of quitting smoking. Other TIC publications include:

- Directory of On-Going Research on Smoking and Health -- the current issue contains over 1,500 research projects from the United States and 40 other countries.
- Bibliography on Smoking and Health -- lists abstracts of 2,000 new studies published annually.
- State Legislation on Smoking and Health -- annual listing of all state laws enacted dealing with taxation, restrictions on smoking in public places, smoking health education in schools, commerce and other areas.
- State and Local Programs in Smoking and Health -- a listing of over 800 programs at the state and local level that serve as a resource guide and referral mechanism for physicians and other health professionals.

The TIC is also responsible for conducting periodic surveys on the smoking habits and characteristics of various segments of the U.S. population; analyzing existing smoking and health data sources; and providing technical assistance to researchers and other health professionals involved in special analysis of smoking and health issues. For the first time, OSH is now able to generate national and statewide smoking prevalence data obtained in cooperation with the the Census Bureau's Current Population Survey. This activity represents the largest survey on smoking ever conducted. A report on this data will be published by the OSH this summer. Another survey on which the Office will be reporting is on public attitudes and beliefs about smoking. This report should be completed by the end of 1986.

The TIC continues to serve as the world's only international clearinghouse for scientific information on smoking and health and is a World Health Organization Collaborating Center for Smoking and Health. By August of this year, the Office is expected to have its entire on-line search and retrieval system available for use by outside organizations and individuals at no cost to the Federal government. Over 40,000 scientific titles will be available via computer access for a small user charge.

Public Information and Education

The public information activities of the OSH have been very successful. Television networks and stations have given OSH Public Service Announcements (PSA's) on the health consequences of smoking more free air time than those produced by any other Federal or nonfederal agency. A recent evaluation found that OSH PSA's aired an average of 25.8 times per month and over 64 percent of these spots were aired during peak viewing times. The value of this air time is in excess of $10 million. Recent examples of the Office's public information and education activities include:

- Secretarial Initiative on Smoking and Pregnancy -- a combination of TV and radio announcements, a news video, posters (in English and Spanish), pamphlets and other materials were used to convey the dangers of smoking by pregnant women.
- A Physician Talks About Smoking -- this talk was prepared by the Office for use by any physician or health care professional who is called upon to speak to medical and lay audiences on smoking and health.
- High School Ads -- a series of public service advertisements was created for high school newspapers. This is the first time this medium has been used b, a Federal health program.
- The Smoking Monkey Campaign -- this public service announcement on the health hazards of smoking was jointly sponsored with the American Cancer Society and proved to be a great success.

One specific comment I would like to make about the public information and education activities of the OSH is that because they do their job so well, their own products are not always highly visible. They often produce public information materials -- PSAs, pamphlets, brochures, draft papers and speeches -- that are used by other organizations, with the credit for that material going to that organization or group. This especially benefits smaller, local community and health organizations that do not have the resources to produce such materials.

In addition to its information and education programs on the health effects of cigarette smoking, as a result of the enactment of the Comprehensive Smokeless Tobacco Health Education Act of 1986 (P.L. 99-252), the Office has been designated as the lead agency for the development of educational programs and materials about the health hazards of the use of smokeless tobacco products.

Regulatory and Reporting Activities

The regulatory and reporting activities of the OSH are its newest areas of responsibility. The enactment of the Comprehensive Smoking Education Act (P.L. 98-474) in 1984 not only statutorily established the OSH, but required the Office to perform several new reporting and regulatory functions. The legislation requires the Office to staff the Interagency Committee on Smoking and Health, including the preparation of a biennial report to Congress on the activities of the Office, as well as the private sector, and about the efforts undertaken by each to inform the public of the health hazards of smoking.

The Office is also charged with the important task of compiling and reporting on cigarette ingredients information to be supplied to the DHHS by cigarette manufacturers as mandated by P.L. 98-474. This ingredients report to Congress must include information regarding any ongoing or proposed research activities on the health effects of tobacco additives and any other information on ingredients which pose a health risk to smokers. This information must be transmitted to Congress on a regular basis and must be made available to individual members of Congress or Congressional Committees upon request.

The comprehensive smokeless education act contains similar provisions for collecting and reporting on additives in smokeless tobacco products. In addition, the law requires a report to Congress describing the effectiveness of health education efforts about the adverse health effects of smokeless tobacco use; smokeless tobacco consumption figures; a description of the health effects of smokeless tobacco use; and identification of health and consumption-related topics appropriate for further research.

So how effective has the Office been in getting its messages across to the public? While direct measurement of this is impossible, the following statistics show that a substantial impact has been made since the Federal government first began its smoking education activities. Total cigarette consumption declined by over 30 billion between just 1982 and 1984. Per capita consumption is now at its lowest level since the 1940's. Except for young females, smoking among all major age, race and sex groups has declined. In just 20 years, smoking prevalence among adult males has decreased by 40 percent. Obviously OSH cannot take full credit for these changes in smoking behavior, however, they have provided strong leadership in this area to which we, in the private sector, have responded enthusiastically.

The OSH accomplishes all of its tasks with minimal resources: a current budget of only $3.24 million and 17 staff positions. In addition, no funding has been added to the OSH budget as Congress has given it increased public education and regulatory responsibilities. In fact, OSH lost three staff positions to PHS management functions in 1985 and the Office suffered a $300,000 budget reduction due to the implementation of the Gramm-Rudman cuts and reductions in funds for consulting services this year. When one takes into account the staggering fact that the tobacco industry spends approximately $2 billion annually on advertising its products it becomes obvious that even the combined resources of the OSH and the voluntary health organizations I represent are not sufficient to counteract the sophisticated advertising techniques employed by the industry to entice individuals to begin or continue smoking.

The President's budget includes $3.47 million for the OSH in FY 1987. We do not believe that this level of funding is sufficient for the Office to carry out all of its current and newly-mandated functions. Therefore, we recommend that the Office receive an FY 1987 appropriation of $4.738 million and that they receive an FTE increase of 8 positions.

The Coalition on Smoking OR Health and its member organizations believe that without the many functions performed by the OSH, the effort to educate the American public and the rest of the world about the health hazards associated with smoking would be far behind where it is today. The Annual Surgeon General's reports are looked upon internationally as the scientific reference on smoking and health related topics. OSH's collection and dissemination of the immense data base of smoking and health research, both completed and ongoing, is an invaluable resource to scientists, health professionals and public health advocacy organizations like ours. Finally, the public health activities and programs developed and implemented by OSH have added immeasurably to the gains that have been made in reducing the single most preventable cause of death in the U.S.: cigarette smoking. I am here today, on behalf of the the Coalition on Smoking OR Health, to urge the Subcommittee to provide adequate funding for this small but most effective Federal office. Hundreds of thousands of lives are depending upon it.

WEDNESDAY, APRIL 30, 1986.

NINCDS

WITNESS

W. KEMP CLARK, AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS, CONGRESS OF NEUROLOGICAL SURGEONS

Mr. NATCHER. Our next witness is Dr. Clark.

Dr. CLARK. Thank you, Mr. Chairman.

Mr. Chairman, and members of the committee, I thank you for the opportunity to appear here today to discuss funding for the National Institutes of Health and more particularly for the National Institute of Neurological, Communicative Disorders, and Stroke.

I am W. Kemp Clark, M.D., Professor of Neurosurgery at the University of Texas, Health Science Center in Dallas. I speak for the American Association of Neurological Surgeons and the Congress of Neurological Surgeons, who represent more than 3,000 neurosurgeons in the United States.

Organized neurosurgery's primary concern is the stability of research support from the National Institutes of Health. We note, with great concern, the atmosphere of uncertainty the President's recent budgets have created in the research community. We were under the impression that last year the Congress and the Executive Branch had reached a mutually acceptable level of support for competing awards only to reach that the recommended level of competing grants for fiscal year 1987 is 5,104 or nearly a 1,000 less than in fiscal year 1986 HHS appropriations signed by the President.

The National Institutes of Health, in our view, needs a reasonable idea of what the future holds for funding in order to effectively carry out its programs. We, therefore, recommend that you consider providing monies in fiscal year 1987 for competing grants at the fiscal year 1985 level of 6,219.

We would also like to address the issue of laboratories and equipment. From our experience, we believe that there is a real need for the Congress to enact a plan for the modernization and updating of existing research facilities and equipment.

While there is presently some ongoing modernization of our national facilities, I fear that it is rather piecemeal and often only done when a few extra dollars are available and without a well-developed plant.

We, therefore, propose that a specific five-year plan be developed and funded to renovate outmoded research laboratories and equipment both for the intramural and extramural programs at the National Institutes of Health.

Unfortunately, Mr. Chairman, we do not have the expertise to offer specific guidelines on the dollar amounts for such an effort for all disciplines. We are prepared to share our specific observations about the needs of the neurosciences.

I am pleased to report to the committee that the support of the Federal Government at the National Institutes of Health and the Veterans Administration has been very helpful. Clinical research in the epidemiology, occupational hazard, economic cost, and treatment efficacy in low back pain. Legislation in this committee last year has now resulted in two years of endeavor in the research community.

Research continues, in an exciting way, in those neurologic diseases which may prove to be due to deficiencies in neurotransmitters, as has been shown in Parkinson's Disease. It may be true in Alzheimer's Disease, as well.

In order to continue these and other efforts in the multi-faceted mission of the NINCDs, we propose a moderate increase in research support.

In my written statement I have given a precise detail of our funding. We thank you for your time and interest.

I want you to know that Neurosurgery in America is grateful for your historic interest in a strong NIH research program.

Mr. NATCHER. Thank you very much for an excellent statement.

[The statement of Dr. Clark follows:]

STATEMENT

of the

AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS

and

CONGRESS OF NEUROLOGICAL SURGEONS

to the

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
U.S. House of Representatives

Presented by

W. Kemp Clark M.D.

RE: Funding for the National Institute of Neurological,
Communicative Diseases, and Stroke
and
The National Institutes of Health

April 30, 1986

Mr. Chairman and members of the Committee, thank you for the opportunity to appear here today to discuss funding for the National Institutes of Health and more particularly for the National Institute of Neurological, Communicative Disorders, and Stroke.

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Organized neurosurgery's primary concern is the stability of research support from the National Institutes of Health. We note, with great concern, the atmosphere of uncertainty the President's recent budgets have created in the research community. We were under the impression that last year the Congress and the Executive Branch had reached a mutually acceptable level of support for competing awards only to read that the recommended level of competing grants for FY 1987 is 5,104 or nearly a 1,000 less than in FY 1986 HHS appropriations signed by the President. The National Institutes of Health, in our view needs to have a reasonable idea of what the future holds for funding in order to effectively carry out its programs. We therefore recommend that you consider providing monies in FY 1987 for competing grants at the FY 1985 level of 6219.

We also want to address the issue of laboratories and equipment. From our experience we believe that there is a real need for the Congress to enact a plan for the modernization and updating of existing research facilities and equipment. While there is presently some ongoing modernization of our National facilities, I fear that it is rather piecemeal and often only done when a few extra dollars are available and without a well developed plan. We therefore propose that a specific five year plan be developed and funded to renovate outmoded research laboratories and equipment both for the Intramural and Extramural programs at the National Institutes of Health. Unfortunately, Mr. Chairman, we do not have the expertise to offer specific guidelines on the dollar amounts for such an effort for all disciplines. We are prepared to share our specific observations about the needs of the neurosciences.

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Research continues, in an exciting way, in those neurologic diseases which may prove to be due to deficiencies in neurotransmittors, as has been shown in Parkinson's Disease. It may be true in Alzheimer's Disease as well.

In order to continue these and other efforts in the multifaceted mission of the NINCDS, we propose a moderate increase in research support. For example, in order to fund the NINCDS programs at a 40% funding rate the following support levels will be necessary:

	1987 Needs at 40% Funding Rate	
	Number	Dollars
1. Research Grants		
A. Projects		
1. Non-Competing	1,356	$229.547
2. Competing	956	162.434
Subtotal Projects	2,312	$396.981
B. Research Centers	44	$ 35,000
C. Other Research	330	19,900
Total Research Grants	2,686	$451,881
2. Training Programs		
A. Individual Awards	253	$ 5,486
B. Institutional Awards	384	7,979
Total Training	637	13,465
3. R & D Contracts	70	$ 14,250
4. Intramural Research		54,450
5. NINCDS Program Direction		19,600
TOTAL		$553,646

Thank you for your time and interest. I want you to know that Neurosurgery in America is grateful for your historic interest in a strong NIH research program.

WEDNESDAY, APRIL 30, 1986.

NATIONAL LIBRARY OF MEDICINE

WITNESSES

DR. JEAN MAYER, TUFTS UNIVERSITY

DR. DONALD DETMER, UNIVERSITY OF UTAH

Mr. NATCHER. Our next witnesses are Dr. Jean Mayer and Dr. Donald Detmer. We will be pleased to hear from you.

Dr. MAYER. Distinguished members, I am Jean Mayer, President of Tufts University, an institution with a major commitment to the health sciences with Schools of Medicine, Dental Medicine and Veterinary Medicine, Graduate Schools of Biomedical Sciences and Nutrition and a national center for the study of human nutrition and aging.

Our faculty clinicians in the health professions, numbering almost 2500 in all schools, provide patient care in more than 50 inhouse and affiliated clinical institutions throughout central New England and beyond. We are an institution with a deep and powerful conviction that modern information technology, available now, provides us the tools for major and fundamental improvements in health care in this country and abroad.

We are equally convinced that despite the current accomplishments achieved by the application of computer and communication technology to problems of biomedical research, education, patient care and health care delivery management, we have barely begun to scratch the potential of what can be done.

There is now universal acceptance of the powerful potential of information technology in all aspects of health care. There is also a growing realization that major gaps existing in our understanding of how information is transformed into knowledge and how that knowledge is then effectively applied to solution of problems.

These are the basic issues of medical informatics and they deserve your immediate attention and support. We believe the Unified Medical Language System, the IAIMS, the Medical Informatics Research and Training Programs of the National Library of Medicine are the most effective means of providing the critically needed national focus required to move ahead in this area.

We join our colleagues in the Ad Hoc Coalition for Biomedical Research in urging a program increase above current service level budget for the National Library of Medicine. In particular, we strongly support an increased allocation of $3,200,000 for the establishment of four Centers of Excellence in Medical Informatics.

I do not appear before you as an expert in medical informatics. I will leave the discussion of specific applications of that discipline to others including my eminent colleague, Vice President Detmer of the University of Utah.

As a nutritionist, I have a deep personal interest and involvement in improving and maintaining the health status of people in this country and around the world. As President of Tufts University, I have a deep personal interest and involvement in improving and maintaining the well-being of our biomedical research, education and patient care programs. I believe the establishment of the

Centers of Excellence Program in Medical Informatics will be of major benefit to both of these interests.

I would like to focus my remarks in two areas: the current desperate shortage of qualified faculty in the area of medical informatics and the necessity of the Centers of Excellence approach to deal with this issue; and the need, especially in times of severe financial restraint, to invest in a program whose goal is more effective use of existing resources.

The dramatic expansion of medical knowledge offers the promise of improving patient care and increasing the length and quality of life.

However, before that promise can be met we must develop the scientific basis for controlling that information and transforming it into useful knowledge. This process has been excruciatingly slow, in part, because of a lack of individuals trained to reach and perform creditable research in this area. Our great need today is to train future medical faculties and to retrain today's faculties in the management of medical information.

It has been strongly recommended that each academic medical center have an identifiable locus of activity in medical informatics to foster research, integrate instruction and encourage appropriate use for patient care. For each center to have a minimum effective unit of three to five faculty would require over 500 well-trained people.

At present, virtually all training in medical informatics is funded by the National Library of Medicine. Unfortunately, the total number of NIM trainees is currently less than 30 with approximately ten being graduated each year.

We recommend an NLM budget which would double that number. But even that number would be insufficient to meet the needs for faculty in most academic medical centers. Over the short run, it will be necessary to cluster our previous faculty resources into groups of sufficient critical size to be effective.

An individual physician trained in medical informatics cannot mount an effective research program in isolation, cannot develop an effective curriculum and, most important, cannot set a role model for students and other faculty to follow.

In order to be effective in recruiting bright young physicians into this career path, we must provide an intellectually stimulating and self-supportive community and a stable environment for research.

Because it is such a new field, it is difficult for young investigators to establish themselves professionally. Because medical faculties have few medical informaticians, criteria for academic advancement rarely include an appreciation of the special problems of basic research in this field.

The time frame for individual projects can be very long and there is often little opportunity to publish in the standard prestigious journals. The Centers of Excellence program with committed support for five years would provide the critical mass and stability for research and training so essential to the developing faculty member. It will also provide a focus for professional recognition of the discipline of medical informatics within the academic medical center.

I am proud to say that my own institution has made some progress in this area. Our Division of Medical Decision Making in the Department of Medicine has made many notable contributions to the field. In addition, we have created a new academic Division of Clinical Decision Making and Information Management in our medical school.

Under the direction of Dr. Stephan G. Pauker, Professor of Medicine and Director of the Medical Decision Making Division at the New England Medical Center Hospital, this new academic unit will be responsible for curriculum development and research activity in medical informatics.

In addition to Dr. Pauker, we have recruited two young physician informaticians who will graduate from an NLM sponsored training program under Dr. Pauker's direction in June. We have invested institutional funds for basic salary support and newly constructed space.

However, it is not yet a center of excellence because the resources are just not there for all the necessary functions. The ability of programs such as ours to flourish depends upon the type of support described by the Centers of Excellence program and, therefore, I support the concept wholeheartedly.

These are difficult times for Federal spending and private institutional spending. During periods of fiscal restraint, it is difficult to request funding for new programs. But during such times it may be wise to make an investment in more effective use of current resources.

Given the substantial past, present and even greater future investments our nation has made and will be making in medical research and health care delivery, it would be wise to invest adequate funds to improve the decision making process and give our health care providers an effective basis for optimizing the use of medical knowledge already available.

At Tufts, despite many pressing needs and extremely limited resources, we felt it essential to invest in a medical informatics program as vital to our education, research and patient care programs. We urge the Congress to do the same.

An important characteristic of medical informatics which may be understated and perhaps under-appreciated is the fact that it is an interdisciplinary field which will increasingly affect every area of health.

As a nutritionist, I see the applications developed under the aegis of medical informatics as being immediately useful to the field of nutrition. I see emerging knowledge management and communication tools enabling really effective interchange not only among medical disciplines but also among all health disciplines and, perhaps most important, beyond.

The teaching and practice of medicine is no longer the sole province of the medical sciences. The science of medicine must be complemented by economics, politics, sociology, history, ethics, philosophy and even religion. As the President of a university where the linking of these disciplines becomes more apparent every day, I see medical informatics providing the means for effectively communicating and sharing the knowledge and expertise of these great disciplines.

In summary, the health professions are just beginning to face what perhaps will be their greatest challenge, the explosion of knowledge and information which is proceeding at a pace which even now outstrips the cognitive styles taught in our schools and our ability to effectively apply it in practice.

Aside from our health care personnel, our greatest biomedical resource is information; scientific and clinical data in amounts and forms almost unmanageable and certainly underutilized; information waiting to be converted to knowledge; knowledge waiting to be transformed into useful applications.

We recognize the need to make basic changes in education and research but are critically constrained in the numbers of trained professionals available and the amount of research that can be done.

Consequently, I recommend specific language in the NLM appropriations which would allow support of four centers of excellence at an annual level up to $800,000 each for periods of at least five years.

Such support is eligible under the existing NIH Center Grant authorization program. Competitive peer review will assure that the best qualified institutions will meet the heavy responsibilities of excellence. I believe the numbers of centers should grow gradually but steadily over the years.

Thank you again for the privilege of addressing the subcommittee in this vital area. I hope my remarks will be useful to you as you consider the budget of the National Library of Medicine and the request for the establishment of Centers of Excellence in Medical Informatics.

Mr. NATCHER. Thank you very much.

[The statement of Dr. Mayer follows:]

Page 1 - Dr. Mayer, verbal testimony, April 30, 1986

Mr. Chairman and distinguished members. Thank you for the opportunity to express my support for the National Library of Medicine and, in particular, its research and training programs in medical informatics. I am Jean Mayer, President of Tufts University. Tufts has a major commitment to the health sciences. We have Schools of Medicine, Dental and Veterinary Medicine, Biomedical Sciences and Nutrition, and a national center for the study of nutrition and aging. We have almost 2500 clinicians on our faculties. They provide patient care in more than fifty in-house and affiliated institutions throughout central New England.

The dramatic expansion of medical knowledge offers the promise of improved health care and increased length and quality of life. Information technology can be a powerful tool. But before its promise can be met, we must develop the scientific basis to transform information into action where it is needed. Enormous banks of data, vast sources of resource information, and proliferating recorded knowledge are scattered and not easily accessible. They are essential for scientific research and bear closely on health care, but how hard it is to get at them, and, once acquired, how time-consuming it is to put the information in useable form. Truly compassionate care depends on informed care. Simple humanity demands that such informed care be universally available. These are the basic issues of medical informatics.

Addressing the issues requires the efforts of highly trained scientists and clinicians in a variety of disciplines, and their efforts will only be successful if adequate resources are made available to them. We believe that the Unified Medical Language System, the IAIMS, and Medical Informatics Research and Training Programs are the most effective ways to provide the national focus required to move ahead in this area. We join our colleagues in the Ad Hoc Coalition for Biomedical Research in urging a program increase above the current service level budget for the National Library of Medicine. In particular, we strongly support an increased allocation of $3,200,000 for the establishment of four Centers of Excellence in Medical Informatics.

Our great need today is to train future medical faculty and to retrain today's faculties in the management of medical information. Yet there is a desperate shortage of qualified faculty in medical informatics. It has been strongly recommended that every academic medical center have an identifiable center of activity in medical informatics, to foster research, integrate instruction, and encourage appropriate use for patient care. If each medical center had a minimum unit of three to five faculty, we would require over five hundred well-trained people nationwide. Unfortunately, the total number of NLM trainees is now less than thirty. About ten are graduated each year. We recommend an NLM budget which would double that number. But even that is not enough to meet the needs in most academic medical centers. The answer lies in the concept of Centers of Excellence.

Over the short run, it will be necessary for medical centers to cluster precious faculty resources into small groups. One physician trained in medical informatics cannot mount an effective research program, develop an effective curriculum, or, most important, set a role model for students and other faculty to follow. To recruit bright young students into this career path, we must provide an intellectually stimulating and supportive community and a stable research environment. We must, in short, have a group of sufficient critical size to be effective. Because medical faculties have few medical informaticians, criteria for academic advancement rarely take into account the special problems of basic research in this field. The time frame for individual projects can be very long and there is often little opportunity to publish in the standard prestigious journals. Thus, the Centers of Excellence program with committed support for five years would provide the critical mass and stability so essential to the developing faculty member. It will also provide a focus for professional recognition of the discipline.

Let me illustrate with Tufts' example. We have set up a Division of Medical Decision Making in our Department of Medicine which has made a number of notable contributions to this field. We have also created a new Academic Division of Clinical Decision Making and Information Management in our medical school. We have invested institutional funds for basic salary support and newly-constructed space. However, it is not yet a center of excellence because the resources are just not there for all the necessary functions. The ability of programs such as ours to flourish depends on the type of support offered by the Centers of Excellence program.

We recognize, both for ourselves and for the nation, how difficult it is to find funds for new programs in a time of fiscal restraint. But this is a program whose goal is more effective use of existing resources. Given the substantial past and present and even greater future investments the country has made and will be making in medical research and health care delivery, it seems most wise to invest adequate funds to improve the decision-making process and to give our health care providers an optimal basis for applying the medical knowledge that is already available in some form, somewhere. We at Tufts felt it essential to invest in a medical informatics program, despite our many pressing needs and extremely limited resources. We hope that the Congress will feel the same.

I should point out that although I have been talking about medical applications, medical informatics is an interdisciplinary field that will affect every area of health. It will be immediately useful in my own field, nutrition, for example. Perhaps most important, these emerging knowledge management and communication tools will permit interchanges among all the disciplines that bear on the medical sciences, complementing the teaching of medicine with, for example, economics, politics, sociology, history, ethics, philosophy, and even religion. As President of a university where the linking of disciplines becomes more apparent every day, I see medical informatics as providing the means to communicate and share the knowledge and expertise of many of the great areas of human knowledge and research.

Aside from our health care personnel, our greatest biomedical resource is information; scientific and clinical data in amounts and forms almost unmanageable and certainly underutilized; information waiting to be transformed into useful applications. We recognize the need to make basic changes in education and research, but are critically constrained by the numbers of trained professionals available and the amount of research that can be done.

Consequently, I recommend specific language in the NLM appropriations which would allow support of four centers of excellence at an annual level of up to eight hundred thousand dollars each for periods of at least five years. Such support is eligible under the existing N.I.H. Center Grant authorization program. Competitive peer review will assure that the best-qualified institutions will meet the heavy responsibilities of excellence. I believe the number of centers should grow gradually but steadily over the years.

Thank you again for the privilege of addressing the Subcommittee in this vital area.

Mr. **Natcher**. Dr. Detmer, we will be pleased to hear from you.

Dr. **Detmer**. Thank you very much.

I am here also to request support for Centers of Excellence in Medical Informatics.

I am a physician and medical educator formerly at the University of Wisconsin in Madison and now at the University of Utah where I am Vice President for Health Sciences.

Everything you have heard this morning is based upon medical knowledge and issues regarding medical knowledge. I consider it most important that Federal programs be available to help the national health community resolve these medical knowledge issues.

For example, at Utah we are currently receiving support from the National Library of Medicine to develop an academic management system. This long term essentially is a grant that allows us to lay careful plans and initiate them in phases so we can link a full range of extensive information and data resources together, coordinate them, and manage them properly. We expect that the resulting integration of information services to have a profound and beneficial effect, not only on our management practices but also on our educational programs.

The exciting potential of this system does not, however, by any means resolve the issues inherent in medical knowledge and its availability. Quite the contrary.

These issues are important scientific problems and for that reason I am here to endorse Federal support for Centers of Excellence in Medical Informatics so we can attack these issues in a more focused way.

Federal support is necessary because the growth of such centers through purely local efforts will be too slow and intermittent to meet national health needs. The information problems of health practitioners have been described many times.

I am sure you have heard them often. They are very real and they are very challenging. These challenges have been addressed by a number of imaginative and creative investigators whose work convinces me that the investigation of modern medical information activity is truly worthy of the most serious scientific investigation on both the fundamental and applied level.

Consequently, it is now appropriate to give support to centers that can increase the supply of persons well educated in the health profession and also in these new information and computer sciences.

Medical informatics first came to my attention when I was at the University of Wisconsin. Experimentation there with the inneractive capabilities of computer terminals led to entirely new insights into how patients can relate—relating to health behaviors and how they can relate to information and in the patient's own capability for assisting significantly in medical diagnosis and treatment.

At the same university, efforts in organizing journal articles, the staff of our "Intellectual Life", lead conveniently to an elegant literature retrieval system which, to the observer, seems to display not just sympathy but even empathy.

Meanwhile, at Latter Day Saints Hospital in Salt Lake and on my own campus, it has been ingenuously harnessed to meet the needs of our hospital communities for organizing hospital and data in an integrated and effective way. These accomplishments, important though they are, are only an indication of what we could expect from a well organized, vigorously directed center where a coordinated scientific team examines medical information issues at depth and at length.

With the stature that recognition is the Center Excellence would convey, work on medical informatics would move even more into the mainstream of clinical activity. The center team would be able to combine or coordinate various disciplinary perspectives to address information issues at both theoretical and applied levels.

I would like to tell you briefly what some of those issues are. The end goal of information knowledge systems is to promote sound medical judgment based on impeccable reasoning. This is medical cognition and we know very little formally about it. Learning more about how physicians make their decisions and how physicians can evaluate decision choices is essential if we are to design computer driven systems that truly assist judgment.

Assistants for judgment or decision support raises numerous ancillary questions of knowledge representation, display of alternatives and tools for mathematical analysis. The latter are especially important when you consider physicians are not necessarily mathematically adept.

Related to these areas is the need to design and develop systematic information delivery mechanisms of every kind. The vast array of data, information and ever proliferating knowledge impels us to find better ways of synthesizing, integrating and displaying responses to clinician's needs and questions.

Centers of Excellence then would become an institutional locus for the education of health professionals and medical information experts in the techniques and problems of using computers and information systems to improve health care. This is best done in academic medical centers that are distinguished for their clinical research as well as for their teaching.

Related activities would be the development and evaluation of innovative courses and curriculum that benefit all students. One of our goals is to make information management by computers one of the skills every health professional should possess. To do so requires vision, leadership, ability to coordinate and requisite concentration of resources.

Another function not usually covered in research projects is the development and design of service applications where we have obligations to the entire community and State. These would most likely concern dissemination of information, professional exchanges by way of electronic networking and some form of distributed computer processing.

Such projects could offer exciting new prospectives on continuing education for all health professionals. Centers of Excellence and medical informatics will go far to helping our educational offering keep pace with ever-changing biomedical science.

Not only will our students leave us well prepared for their various careers in community practice, but the Centers of Excellence would also implement activities and projects which can help the practitioner keep up-to-date in an increasingly information driven environment and to make decisions which reflect as closely as possible the current state of the medical art.

This is no easy task, particularly in a State like Utah and its large inner-mountain west area that is about 50 percent of the land mass of the U.S. where there are many relatively isolated communities separated by harsh climate and rugged terrain where even the most advanced telecommunications and computer technologies will require a great deal of careful development pursued in rigorously scientific ways.

As a means of conveying support, I recommend the well-established Center Grant, as administered by the National Institutes of Health. This mechanism has enabled the growth of other biomedical communities and could surely do the same for medical informatics. The number of truly able people in this field is small—one Center goal would be, in fact, to expand the pool of qualified personnel—so that it would be best to begin with a small number, five or six Centers, but to support these at a level adequate for the range of functions I have indicated above.

My suggestion would be for approximately $800,000 each, for five or six, with a fairly extensive project period. The directors of these Centers should be confident of at least five years of initial support.

I believe that the centers will attract not only the attention and respect of local or institutional medical communities, but that their influence will spread beyond institutional boundaries because of the quality of research performed and the beneficial effects of scientifically valid new modalities for managing our vast knowledge resources.

Thank you for this opportunity to present my views.

[The statement of Dr. Detmer follows:]

STATEMENT BY
DON E. DETMER, M.D.

Vice President for Health Sciences
University of Utah
Salt Lake City, Utah

Testimony Before the House Appropriations Committee:
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

Subject of Testimony: Federal Support for
Centers of Excellence in Medical Informatics
(Agency: National Library of Medicine)

April 30, 1986

Mr. Chairman: I am a physician and medical educator, formerly with the University of Wisconsin and now with the University of Utah where I serve as vice president for health sciences. I have long been concerned with issues regarding medical knowledge, and I consider it most important that Federal programs are available to help the national health community in resolving these issues. For example, at Utah, we are currently receiving support from the National Library of Medicine to develop an Integrated Academic Information Management System. Such a grant gives us the means to lay careful plans, and to initiate them in phases, so that eventually we will be able to coordinate and manage better the full range of our extensive information and data resources. We expect the resulting integration of information services to have a profound and beneficial effect not only on our management practices, but also on our educational programs.

The exciting potential of such a system does not, however, by any means resolve the issues inherent in medical knowledge and its availability. Quite the contrary, these issues are important scientific problems, and for that reason I am here to endorse Federal support for Centers of Excellence in Medical Informatics so that we can attack these issues in a more focused way. Federal support is necessary because the growth of such Centers through purely local efforts will be too slow and intermittent to meet national health needs.

The information problems of health practitioners have been described many times. They are very real and they are very challenging. These challenges have been addressed by a number of imaginative and creative investigators, whose work convinces me that the investigation of modern medical information activity is truly worthy of the most serious scientific investigation on both the fundamental and the applied level. Consequently, it is now appropriate to give support to Centers that can increase the supply of persons well educated in the health professions and also in the new information and computer sciences.

Medical Informatics first came to my attention at the University of Wisconsin. Experimentation with the interactive capabilities of computer terminals there has lead to entirely new insights into patient behavior, and in the patient's own capability for assisting significantly in medical diagnosis and treatment. At the same university, efforts at organizing journal articles, the staff of our intellectual life, led eventually to an elegant literature retrieval system which, to the observer, seems to display not just sympathy, but even emphathy. Meanwhile, at Latter Day Saints' Hospital in Salt Lake City and here at our university, computer technology has been ingeniously harnessed to the needs of our hospital community for organizing information and data in an integrated, efficient way.

These accomplishments, important though they are, are only an indication of what we could expect from a well-organized, vigourously directed Center where a coordinated scientific team examines medical information issues in depth and at length. With the stature that recognition as a Center of Excellence would convey, work on Medical Informatics would move more into the mainstream of clinical activity. The Center team would be able to combine or coordinate various disciplinary perspectives to address information issues at both theoretical and applied levels. Here are some of these issues.

- The end goal of information-knowledge systems is to promote sound medical judgment based on impeccable reasoning. This is medical cognition, and we know very little formally about it. Learning more about how physicians make their decisions and how physicians can evaluate decision choices is essential if we are to design computer-driven systems that truly assist judgment.

- Assistance for judgment, or decision support, raises numerous ancillary questions of knowledge representation, display of alternatives, and tools for mathematical analysis. The latter are especially important when you consider that physicians are not necessarily mathematically adept.

- Related to these areas is the need to design and develop systematic information delivery mechanisms of every kind. The vast array of data, information, and ever proliferating knowledge impels us to find ways of better synthesizing, integrating, and displaying responses to clinicians' questions or needs.

Centers of Excellence, then, would become an institutional locus for the education of health professionals and medical informatics experts in the techniques and problems of using computers and information systems to improve health care. This is best done in academic medical centers that are distinguished for their clinical research as well as for teaching. Related activities would be the development and evaluation of innovative courses and curricula that benefit all students. One of our goals is to make information management by computers one of the skills every health professional should possess. To do so requires vision, leadership, ability to coordinate, and requisite concentration of resources. Another function, not usually covered in research projects, is the development and design of service applications where we have obligations to the entire community and state. These would most likely concern dissemination of information, professional exchanges via electronic networking, and some form of distributed computer processing. Such projects could offer exciting new perspectives on continuing education for all health professionals.

Centers of Excellence in Medical Informatics will go far to helping our educational offerings keep pace with ever-changing biomedical science. Not only will our students leave us well prepared for their various careers in community practice, but the Centers of Excellence would also implement activities and projects which help the practitioner keep up to date in an increasingly information-driven environment, and to make decisions which reflect, as closely as possible, the current state of the medical art. This is no easy task, but in a state like Utah where there are many relatively isolated communities, separated by harsh climate and rugged terrain, even the most advanced of the telecommunications and computer technologies will require a great deal of careful development, pursued in rigorously scientific ways.

As a means of conveying support, I recommend the well-established Center Grant, as administered by the National Institutes of Health. This mechanism has enabled the growth of other biomedical communities and could surely do the same for medical informatics. The number of truly able people in this field is small--one Center goal would be, in fact, to expand the pool of qualified personnel--so that it would be best to begin with a small number, 5 or 6 Centers, but to support these at a level adequate for the range of functions I have indicated above. My suggestion would be for approximately $800,000 each, for 5 or 6, with a fairly extensive project period. The directors of these Centers should be confident of at least five years of initial support.

I believe that the Centers will attract not only the attention and respect of local or institutional medical communities, but that their influence will spread beyond institutional boundaries because of the quality of research performed and the beneficial effects of scientifically valid new modalities for manageing our vast knowledge resources.

Thank you for this opportunity to present my views.

Mr. NATCHER. Mr. Conte.

Mr. CONTE. I want to add my own personal welcome to Dr. Mayer. He leads one of the greatest institutions in the country, Tufts University. It has been my privilege to work with the Doctor and the University over the years. It is certainly a pleasure to see you here today looking so well and hearing your words of wisdom.

Thank you, Mr. Chairman.

Mr. NATCHER. Gentlemen, thank you very much.

WEDNESDAY, APRIL 30, 1986.

HEALTH SERVICES RESEARCH

WITNESS

DR. DONALD STEINWACHS, DIRECTOR, HEALTH SERVICES RESEARCH AND DEVELOPMENT CENTER, JOHNS HOPKINS UNIVERSITY; REPRESENTING THE ASSOCIATION OF HEALTH SERVICES RESEARCH

Mr. NATCHER. Our next witness is Dr. Steinwachs.

Doctor, glad to have you before the committee.

Dr. STEINWACHS. Thank you, Mr. Chairman, members of the committee. It is a pleasure to appear before you today. I am the Director of the Health Services Research and Development Center at Johns Hopkins and a member of the Board for Health Services Research, a national organization for the promotion of health services research. As you know, Mr. Chairman, and members of the committee, health services research is that area primarily responsible for bringing you the kinds of information you need on the financing, the organization, the technology, the impact or changes in manpower in the health care industry and what relationships those have to changes in the quality of care and to the cost of the health care system.

Over ten percent of the gross national product is currently going into health services and the problems of health care costs are not going to disappear rapidly. Evidence from as recently as this past year shows that health care costs are rising more rapidly than the consumer price index are likely to continue to do so.

At the same time the programs the Congress has put into place have moved to hold down costs under the medical care program and hospitalization issues are being raised about the quality of care and the impact it is having on the elderly, shorter hospital stays, transitions into community care and efforts to keep patients out of nursing homes.

We know very little about the impact of many of these new programs and, as you are well aware, the amount of investment currently being made in research is rather small compared to over $90 billion a year that you are providing support services under medicare and medicaid. I and others are very concerned that these investments re not going to be adequate to meet your future needs, that they are both methods and sets of information that you will need and that the public will need in order to assure that the services received are adequate in terms of quality and that they are efficient in terms of cost and use of resources.

As you are well aware, your previous investments in health services research have been productive. Your investments in the development of diagnosis-related groups have been used under the medicare prospective payment system and have been the method to try and control the rapidly rising medical costs of this country.

Methods to look at quality of care and to make judgments about the appropriateness of hospitalizations are being used by the peer review organization in this country to try and assure that the elderly are getting appropriate hospital services.

Other information that has been produced has pointed the direction for the introduction of ambulatory surgery to replace hospital administrations and to help cut costs, but at the same time new issues are arising.

The shortened hospital stays for the elderly are creating concerns about the transition into the community and the ability of community services to be there when they are needed, and to the extent, and who is going to pay for those services.

At the same time new types of health care, competitive plans are being introduced about which we know little and yet the American public is seeking guidance.

New technologies are being introduced and technologies have both quality and cost implications. It is clear that the Federal Government needs to play the leadership role in health services research. The Federal Government is the major purchaser of health care in this country and the public looks to the Federal Government in its role as a regulator of technology, a regulator of drugs and other services.

I am here to support the request that the National Center for Health Services Research and Health Care Technology Assessment be fully funded at $24 million for the coming year and that the Office of Research Demonstrations be funded at a level of $40 million.

Indeed, this is a rather small expenditure for an over $90 billion medicare and medicaid set of programs that you are responsible as the Congress for administering. It is clear the kinds of information you have used in the past has drawn on the field of health services research and every expectation is that you will continue to have needs for information that draw out of this field.

I very much appreciate the opportunity to appear before you. If there are any questions that I can answer, I would be very happy to do so.

[The statement of Dr. Steinwachs follows:]

Statement of the
Association for Health Services Research
on the FY 1987 Appropriation for the
National Center for Health Services Research/
Health Care Technology
and the
Health Care Financing Administration's
Office of Research and Demonstrations
to the
House Labor/HHS/Education Subcommittee on Appropriations
Presented by
Donald Steinwachs, Ph.D.
April 30, 1986
11:30 a.m.

Mr. Chairman, I am Donald Steinwachs, Director of the Health Services Research and Development Center at the Johns Hopkins University.

I am pleased to have this opportunity to present testimony in support of funding for health services research at the National Center for Health Services Research and Health Care Technology Assessment, a component of the Public Health Service, and the Health Care Financing Administration's Office of Research and Demonstrations.

I am a member of the Board of Directors and appearing on behalf of the Association for Health Services Research, a national organization dedicated to promoting, strengthening, and improving health services research. This particular area of study serves as the primary source of information about the financing, organization and delivery of health services, and related provider and consumer behavior.

Mr. Chairman and members of the Committee, the relative size of the public investment in research and development related to personal health care services has not kept pace with the extraordinary growth in the size and complexity of health care institutions and financing arrangements. As you know, over 10 percent of the GNP is now going into personal health care services. Furthermore, the health care system is going through what many have characterized as a revolution -- a time when old models of providing and paying for services are being discarded in favor of new alternative delivery systems intended to provide more cost-effective care. Given these enormous -- and ever increasing -- costs and these rapid changes in the health care system, it is alarming that so small an investment is being made to explore and evaluate new ways of providing cost-effective and high quality care to our citizens.

The membership of the Association of Health Services Research believes it is important that Federal governmental action be taken to deal with these problems. No other level of government, nor the private sector, can deal with these issues. Furthermore, the Federal share of total personal health care services expenditures is by far the largest single segment of national health care investment, with the Medicare and Medicaid programs expected to cost $94.9 billion dollars in fiscal 1987. The kind of research and public policy development which is needed will have its most immediate impact in the public sector.

In brief, Mr. Chairman, we believe that Congress will not have available, during the next 10 years the information necesary to make sound policy decisions about the $600 billion to $1 trillion health care system, of the 1990's -- and especially the Medicare and Medicaid programs -- unless support for health services research is increased.

The upward pressures on the health care system are now being felt by this subcommittee. For example, the President's 1987 budget request asked for an appropriation of $19.8 billion for the supplementary medical insurance component of the Medicare program. This is an increase of $1.7 billion or 9.5 percent over 1986. By 1990 this committee will be asked to appropriate in excess of $30 billion for the supplementary Medical insurance program. This rate of growth threatens the ability of this committee to fund discretionary health programs, including research programs such as the National Institutes of Health.

Information generated by health services research provides the only resource Congress will have to evaluate alternatives for change and to monitor the impact of those decisions on consumers, providers and payers of care. Without this information, policymakers will be shooting in the dark -- a dangerous way to make policy, I think we would all agree.

During the 1970's and early 1980's Congress relied on health services research extensively in developing reforms in Medicare and Medicaid programs. For example:

- The Medicare prospective payment system (PPS) based on diagnostic related groups (DRG's) is a direct result of a long term commitment of health services research. In 1969 NCHSR awarded a grant to Yale University that led to the development of a reimbursement concept using DRG's. By 1974, when the concept had been refined, continuation of the work in an operational setting was supported by HCFA. This work culminated in the passage of the Medicare PPS program which incorporated DRGs as the basis of its new reimbursement system.

Savings from PPS in 1986 alone are projected to be $1.8 billion dollars, more than the cumulative, combined budgets of NCHSR and HCFA for the past 15 years!

* Ambulatory surgery demonstrations revealed savings ranging from 3 percent to 40 percent depending on the procedure. Thus, based on these findings Congress in the 1980 Reconcilation Act changed the reimbursement for ambulatory procedures.

* Health services research demonstrated that providing health care in prepaid plans such as health maintenance organizations saved money. Based on this information, Congress passed legislation encouraging the use of prepaid plans -- or competitive medical plans -- under Medicare and allowed capitation experiments under Medicaid.

These are but a few examples of how Congress has depended on health services research.

Although past contributions of health services research have helped to slow down the rate of growth of health care expenditures, these expenditures are still growing more rapidly than the economy as a whole.

It is obvious to all who look at the data that the health care system is extremely expensive and complex. However, Congress, the administration, and society as a whole do not know very much about the value of what we are getting for our health care dollar. We don't know how wisely or improvidently we may be spending our limited Medicare and Medicaid dollars. And not knowing frustrates all of us - elected official, administrator, and researcher.

Recently, the Medicare Board of Trustees projected trust fund bankruptcy in 1996 unless Congress raises revenue by 28 percent or decreases spending by 22 percent. Gentlemen, I don't have to tell you that this is easier said than done. It is likely that solvency of the Trust Funds will be guaranteed through decreases in spending, not increases in revenue. Faced with enormous potential cuts in expenditures, Congress will need considerable data and information to develop policies which will produce the required savings while continuing to provide access to quality health care for our elderly citizens. Where will this information come from? The health services research community.

Mr. Chairman, we recognize that the rising costs of health care are a critical problem facing the Congress. But we also want to emphasize that another, equally important problem is emerging -- that is the concern over the impact of the Medicare PPS system and other health care system changes is having on access and quality of care. Are the elderly being pushed out of hospitals before they are ready to care for themselves? Are shorter hospital stays creating a need for another level of services and if so, are these services available? Who pays for these services? Do shorter hospital stays create an increase in readmissions, which would have an impact on the cost and quality of health care? Who can answer these difficult questions? Again, the health services research community.

Mr. Chairman, at the federal level there are two major agencies responsible for funding and conducting health services research:

> The National Center for Health Services Research/Health Care Technology Assessment is the focal point for broad based health services research and technology assessment.
>
> The Office of Research and Demonstrations/Health Care Financing Administration supports research, demonstrations and evaluations directed at specific operational problems of the Medicare and Medicaid programs.

Some examples of on-going research are:

- A study to assess the impact of the Medicare prospective payment system on the quality of inpatient care received by Medicare patients is being conducted.
- Developing and testing alternatives for paying home health agencies on a prospective basis for services provided under the Medicare and Medicaid programs is the focus of a major national demonstration effort.
- Research is underway to determine whether planning for follow-up care for patients age 60 and older before they leave the hospital can achieve better levels of functioning.
- A review of the programs established by various medium and large firms nationwide to control health care costs is being conducted. The study will estimate the cost savings and the policy implications of these innovations.

Mr. Chairman, the proposed 1987 funding levels for the Center and HCFA's research program are inadequate to produce the data needed to institute reforms in the Medicare and Medicaid programs, to achieve the savings needed to produce long-term solvency of the Medicare hospital trust fund, and to achieve a slowing of the rapid growth in the cost of the supplemetary medical insurance (Part B) program.

With these facts in mind, we respectfully request an appropriation in 1987 for the National Center for Health Services Research and Health Care Technology Assessment of $24,000,000 and a funding level for the Health Care Financing Administration Office of Research and Demonstration of $40,000,000. These amounts are tiny when you consider that federal health expenditures for Medicare and Medicaid were $93.4 billion last year.

This concludes my testimony, I will be happy to answer any questions.

Mr. DWYER [presiding]. Thank you, Doctor. Thank you for your statement.

WEDNESDAY, APRIL 30, 1986.

OLDER AMERICANS ACT PROGRAMS

WITNESS

ANN TURPEUA, SECRETARY, THE NATIONAL CAUCUS AND CENTER ON BLACK AGED

Mr. DWYER. Our next witness is Ms. Ann Turpeua, the Secretary for the National Caucus and Center on Black Aged.

Ms. TURPEUA. Mr. Chairman, members of the appropriations subcommittee, I am Ann Turpeua, an officer of the National Caucus and Center on the Black Aged. We appreciate the opportunity to testify at your hearing on funding for aging services activities.

Because our time is limited, I will condense our written testimony, a full copy of which has been submitted for the record.

First, NCBA urges the subcommittee to approve $326 million for the Senior Community Services Employment Program. This is the same amount as recommended by the Administration for fiscal year 1987. Moreover, this request would match the funding level approved by Congress for fiscal years 1985 and 1986.

Title V has been one of the most effective programs ever developed for the elderly, black and other older Americans. It is an enormously popular program which could easily be funded substantially greater than the current amount.

NCBA's Senior Employment Program typically has several applicants for each position available. Our situation is not unique because other national sponsors also have many more applicants than available positions.

Consequently, we do not advertise as much as we would prefer because NCBA does not want to create false hopes for low-income older Americans who are ready, willing and able to work if given the opportunity.

NCBA is recommended a hold-the-line funding level—even though the need is clearly greater, and the money would be spent well. This appropriation would restore the number of Title V positions to 63,784, the current number. The Gramm-Rudman-Hollings amendment will reduce the number of Title V jobs for 2,832 on July 1.

Title V has not only been an effective program, but one that has been responsive to the needs of the minority aged. About one out of every three—34.8 percent—enrollees is a minority elderly person. Aged blacks account for 22.8 percent of all SCSEP participants.

Over the years, Title V has consistently received strong bipartisan support from the Congress because it has been an extra-ordinarily successful program. The SCSEP has enabled low-income older Americans to improve their economic well-being while providing much-needed and beneficial services in their communities.

The program has not been marred by fraud and abuse. Its administrative costs are low. Title V has been effective in moving older Americans into private sector employment. The unsubsidized placement rate reached 21.2 percent during the 1984–85 program year. In short, Title V has taken some of the most economically deprived older Americans in our society, and has provided them with a new lease on life.

Older Americans Act/Administration on Aging.—NCBA further urges the subcommittee to fund Older Americans Act programs under the direction of the Administration on Aging at their fiscal year 1986 levels before the sequestration order became effective. This is essentially the same as the Administration's request, with one exception. The Administration is calling for a 50 percent reduction for Title IV research, training and special projects.

We strongly urge the subcommittee to reject this measure. Title IV has already sustained hefty cuts during the early years of this Administration. A $12.5 million funding level, in our judgment, would seriously cripple this program. Title IV is necessary to complement Title III supportive and nutrition services. It is also vital to develop the cadre of trained personnel to serve older Americans now and in the future.

NCBA, therefore, recommends that funding for Title IV be frozen at the congressionally-approved appropriation levels for fiscal years 1985 and 1986, $25 million. We further recommend that other Older Americans Act programs be funded at their pre-sequestration fiscal year 1986 level.

NCBA also recommends that the subcommittee approved report language to encourage State and area agencies on aging to promote minority participation in Title III supportive and nutrition services. This is necessary because the minority aged's participation rate has dropped sharply in recent years. The older minority participation rate for Title III supportive services has declined by 19.7 percent, from 21.9 percent in fiscal year 1980 to 17.5 percent in 1984.

A similar pattern exists for the nutrition program for the elderly. The minority participation rate has declined by 8.9 percent, from 19 percent in 1980 to 17.3 percent in 1984.

We, therefore, urge the subcommittee again to incorporate specific report language to help assure that aged minorities are served more equitably. This is particularly important because elderly minorities are typically two to three times as likely to be poor as aged whites.

We also urge the subcommittee to approve report language to promote the funding of historical black colleges. We believe this is necessary to encourage more minorities to enter the field of aging and to focus more attention on the special services needs of older blacks.

In conclusion, the National Caucus and Center on Black Aged is recommending a hold-the-line budget for Older Americans Act programs, although a need exists for greater funding to respond to the major problems confronting older blacks and other older Americans.

The funding levels, with one exception, parallel the Administration's budget recommendations and amounts approved earlier by this subcommittee and Congress for fiscal year 1986. We, therefore, urge the subcommittee to approve these measures when the fiscal year 1987 Labor-HHS-Education Appropriations bill is considered.

Thank you, Mr. Chairman.

Mr. **Dwyer**. Thank you, Ms. Turpeua, for your statement. Thank you very much.

[The statement of Ms. Turpeua follows:]

STATEMENT BY

ANNE B. TURPEAU

NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

ON

FUNDING FOR OLDER AMERICANS ACT PROGRAMS

BEFORE THE

SUBCOMMITTEE ON LABOR-HHS-EDUCATION
HOUSE COMMITTEE ON APPROPRIATIONS

APRIL 30, 1986, 11:40 A.M.

Mr. Chairman and Members of the Labor-HHS-Education Appropriations Subcommittee, the National Caucus and Center on Black Aged appreciates the opportunity to testify at your hearing on funding for aging services activities. We fully recognize that your time is limited. Consequently, we shall keep our remarks brief.

NCBA's testimony will concentrate primarily on two key areas: (1) the Title V Senior Community Service Employment Program, which is under the direction of the Department of Labor, and (2) the remaining Older Americans Act programs which are administered by the Administration on Aging.

Senior Community Service Employment Program

First, NCBA urges the Subcommittee to approve $326 million for the Senior Community Service Employment Program (SCSEP). This is the same amount as recommended by the Administration for fiscal year 1987. Moreover, this request would match the funding level approved by Congress for FYs 1985 and 1986.

Title V has been one of the most effective programs ever developed for elderly Blacks as well as other older Americans. It is an enormously popular program which could easily be funded substantially greater than the current amount.

NCBA's Senior Employment Program typically has several applicants for each position available. Our situation is not unique because other national sponsors also have many more applicants than available positions. Consequently, we do not advertise as much as we would prefer because NCBA does not want to create false hopes for low-income older Americans who are ready, willing and able to work if given the opportunity.

NCBA is recommending a $326-million appropriation -- essentially a hold-the-line funding level -- even though the need is clearly greater, and the money would be spent well. This appropriation would restore the number of Title V positions to 63,784. Currently, the SCSEP has 63,784 positions. However, the 4.3-percent sequestration order under the Gramm-Rudman-Hollings amendment will reduce the number of Title V jobs by 2,832 on July 1, from 63,784 to 60,952.

Title V has not only been an effective program, but one that has been responsive to the needs of the minority aged. About one out of every three (34.8 percent) enrollees is a minority elderly person. Aged Blacks account for 22.8 percent of all SCSEP participants.

Over the years, Title V has consistently received strong bipartisan support from the Congress because it has been an extraordinarily successful program. The SCSEP has enabled low-income older Americans to improve their economic well-being while providing much-needed and beneficial services in their communities. The program has not been marred by fraud and abuse. Its administrative costs are low. Title V has been effective in moving older Americans into private sector employment. The unsubsidized placement rate reached 21.2 percent during the 1984-85 program year. In short, Title V has taken some of the most economically deprived older Americans in our society, and has provided them with a new lease on life.

It is a program that has worked extraordinarily well over the years -- for our nation, the older enrollees, and the communities they serve. For these reasons, we reaffirm that the SCSEP should be funded at $326 million for FY 1987, the same amount as recommended by the Administration.

Older Americans Act/Administration on Aging

NCBA further urges the Subcommittee to fund Older Americans Act programs under the direction of the Administration on Aging at their FY 1986 levels before the sequestration order became effective. This is essentially the same as the Administration's request, with one exception. The Administration is calling for a 50-percent reduction for Title IV research, training and special projects.

We strongly urge the Subcommittee to reject this measure. Title IV has already sustained hefty cuts during the early years of this Administration. A $12.5 million funding level, in our judgment, would seriously cripple this program. Title IV is necessary to complement Title III supportive and nutrition services. It is also vital to develop the cadre of trained personnel to serve older Americans now and in the future.

NCBA, therefore, recommends that funding for Title IV be frozen at the congressionally-approved appropriation levels for FYs 1985 and 1986: $25 million. We further recommend that other Older Americans Act programs be funded at their pre-sequestration FY 1986 levels: $265 million for supportive services and senior centers; $336 million for the congregate meals; $67.9 million for home-delivered meals; $7.5 million for grants to Indian tribes; and $200,000 for the Federal Council on the Aging.

An estimated $223 million metals could be served to older Americans during FY 1987 with this appropriation, including 160 million in group settings and 63 million home-delivered meals. Moreover, 9.3 million older Americans would be able to receive a wide range of supportive services, such as home health care, homemaker services, legal services, transportation, information and referral and numerous others.

NCBA also recommends that the Subcommittee approved report language to encourage state and area agencies on aging to promote minority participation in Title III supportive and nutrition services. This is necessary because the minority aged's participation rate has dropped sharply in recent years. The older minority participation rate for Title III supportive services has declined by 19.7 percent, from 21.9 percent in FY 1980 to 17.5 percent in 1984. In fact, the minority participation rate for supportive services has fallen every year since 1980 except for 1982, when it remained unchanged.

A similar pattern exists for the nutrition program for the elderly. The minority participation rate has declined by 8.9 percent, from 19.0 percent in 1980 to 17.3 percent in 1984.

A recent Civil Rights Commission report and other earlier studies have concluded that older minorities have been underserved by Administration on Aging programs, especially when measured against their greater need for services. We, therefore, urge the Subcommittee again to incorporate specific report language to help assure that aged minorities are served more equitably. This is particularly important because elderly minorities are typically two to three times as likely to be poor as aged Whites. Almost one out of every two Blacks 65 or older is either poor or marginally poor.

We also urge the Subcommittee to approve report language to promote the funding of historical Black colleges. We believe this is necessary to encourage more minorities to enter the field of aging and to focus more attention on the special services needs of older Blacks.

Conclusion

In conclusion, the National Caucus and Center on Black Aged is recommending a "hold-the-line" budget for Older Americans Act programs, although a need exists for greater funding to respond to the major problems confronting older Blacks and other older Americans. We are making these recommendations because of the tight budget situation.

Our proposals, we strongly believe, are realistic, reasonable, and substantively sound. The funding levels, with one exception, parallel the Adminstration's budget recommendations and amounts approved earlier by this Subcommittee and Congress for FY 1986. We, therefore, urge the Subcommittee to approve these measures when the FY 1987 Labor-HHS-Education Appropriations bill is considered.

WEDNESDAY, APRIL 30, 1986.

OLDER AMERICANS ACT; COMMUNITY SERVICE EMPLOYMENT

WITNESSES

C. KERMIT PHELPS, VICE PRESIDENT, BOARD OF DIRECTORS, AMERICAN ASSOCIATION OF RETIRED PERSONS

SCOTT MARSHALL, SENIOR LEGISLATIVE COORDINATOR, DEPARTMENT OF FEDERAL AFFAIRS

Mr. DWYER. Our next witnesses are Dr. C. Kermit Phelps and Scott Marshall.

Mr. PHELPS. On behalf of the 22,000,000 members of the American Association of Retired Persons, thank you for this opportunity to testify concerning fiscal year 1987 funding for programs under this subcommittee's jurisdiction.

Our testimony will focus primarily upon Titles III, IV and V of the Older Americans Act, the Low Income Home Energy Assistance Program, the Social Services Block Grant Program, and the Community Services Block Grant.

Although demand for services under these worthwhile programs continues to grow, we recommend that funding for fiscal year 1987 should remain at fiscal year 1986 levels, prior to the 4.3-percent automatic spending reduction authorized by the Gramm-Rudman-Hollings Balanced Budget amendment.

In addition, we also recommend to the subcommittee that adequate funding for claims administration expenses under medicare is necessary in order to avoid hardship to beneficiaries.

The Association recommends a freeze in funding for Older Americans Act programs at the fiscal year 1986 levels, without regard to the 4.3-percent automatic spending reduction under the Gramm-Rudman-Hollings Balanced Budget amendment.

This would effectively fund Older Americans Act programs at $701,600,000; the Federal Council on the Aging, $200,000; supportive services and senior centers, $265,000,000; congregate meals, $336,000,000; home-delivered meals, $67,900,000; research, training and demonstration projects, $25,000,000; and grants to Indian tribes, $7,500,000.

These amounts match the Administration's funding request for AOA/Older Americans Act activities, with the exception of the Title IV research, training and demonstration program, which was mentioned in the previous speech.

The Administration requests $12,500,000 for Title IV. We urge the subcommittee to reject this proposal and fund Older Americans Act research, training and demonstration activities at $25,000,000 as was appropriated in fiscal year 1986.

Funding for Title IV has yielded impressive results, despite a modest investment. Some of the most innovative and effective programs in the field of aging have evolved from Older Americans Act demonstrations, including the nutrition program for the elderly, Foster Grandparents, the Retired Senior Volunteer Program, educational television activities, legal services, student training and improvement of services to minority older persons.

Today, many aged persons are able to live independently in their own homes because of Title III supportive services. The congregate meals program, for example, provides more than just a nutritious meal.

It also offers an opportunity for older Americans to meet and talk with others. Moreover, the home-delivered meals program has enabled many older Americans to live independently in their home, rather than be placed in a nursing home at a much higher public cost.

We further urge that the Title V Senior Community Service Employment Program be funded at $326,000,000, the same amount as the Administration recommendation for fiscal year 1987. This also equals the fiscal year 1986 Congressional appropriation without regard to the 4.3-percent reduction under the sequestration order.

A $326,000,000 funding level would restore 2,832 positions for Title V, which were cut under the automatic spending reduction. The effect is to provide employment opportunities for 63,784 low-income older Americans in a wide range of useful activities.

This takes on added importance now because unemployment jumped by 11 percent for persons 55 or older, from 576,000 in January to 638,000 in March 1986.

Moreover, the number of persons 55 or older in the civilian labor force has declined by 235,000 during the past year, from 15,023,000 in March 1985 to 14,788,000 in March 1986.

In marked contrast, the number of individuals 16 to 54 years old in the civilian labor force grew by 2,107,000 during the same period, from 100,312,000 in March 1985 to 102,419,000 in March 1986.

The Senior Community Service Employment Program has been extraordinarily effective for our Nation, the older participants, and the communities they serve. The essence of the program is to enable low-income older Americans to help themselves while helping others in their communities.

AARP supports funding of the Low Income Home Energy Assistance Program at the fiscal year 1986 level of $2,100,000,000, the same level proposed by the Administration. LIHEAP is extremely important to older Americans, who are especially vulnerable to heat stroke and hypothermia.

The Association supports funding of the Social Services Block Grant at no less than the current level of $2,700,000,000. SSBG provides critically important services that help low-income older Americans and others maintain their independence and avoid inappropriate institutionalization.

Among services funded by SSBG that keep individuals in their homes as long as possible are homemaker, home chore services, home-delivered meals, and transportation. Adult day care and protective services, also funded by the grant, are designed to prevent or remedy abuse and exploitation of both older adults and children.

The need for social services is expanding as the elderly population grows. Demand has accelerated with the early release of patients from hospitals under the Diagnosis Related Group system.

If essential services are not available in the community to support such patients upon their discharge from hospitals or skilled nursing care facilities, it is inevitable that greater costs lie ahead.

The Association recommends that the Community Services Block Grant, funded at $368,000,000 this year, be continued at the same level in fiscal year 1987. A GAO study recently found that CSBG funds are used for both services and administration, frequently supporting the administration of other Federal programs that could not otherwise fulfill their missions.

For instance, the Federal Weatherization Assistance Program has a 5-percent cap on spending for administration; CSBG funds cover remaining costs.

AARP urges this subcommittee to approve adequate funding for administrative expense reimbursement to medicare carriers and intermediaries. Adequate funding is necessary in order to assure expedient and efficient service in the administration of the medicare program.

AARP appreciates the subcommittee's careful consideration of these recommendations and stands ready to work closely with members and staff as you proceed toward markup of a bill for fiscal year 1987.

Thank you very much.

Mr. Dwyer. Thank you, Dr. Phelps. Thank you, Scott Marshall. Thank you both for being here this morning.

[The statement of Mr. Phelps follows:]

STATEMENT OF

C. KERMIT PHELPS, VICE PRESIDENT

BOARD OF DIRECTORS

AMERICAN ASSOCIATION OF RETIRED PERSONS

ON

FY 1987 LABOR, HEALTH AND HUMAN SERVICES, & EDUCATION

APPROPRIATIONS BILL

(OLDER AMERICANS ACT, LOW INCOME HOME ENERGY ASSISTANCE, SOCIAL SERVICES BLOCK GRANT PROGRAM, COMMUNITY SERVICES BLOCK GRANT, MEDICARE)

BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, & EDUCATION

OF THE

COMMITTEE ON APPROPRIATIONS

U. S. HOUSE OF REPRESENTATIVES

APRIL 30, 1986

On behalf of the 22 million members of the American Association of Retired Persons thank you for this opportunity to testify concerning FY 1987 funding for programs under this Subcommittee's jurisdiction. Our testimony will focus primarily upon Titles III, IV, and V of the Older Americans Act, the Low Income Home Energy Assistance Program, the Social Services Block Grant Program, and the Community Services Block Grant. Although demand for services under these worthwhile programs continues to grow, we recommend that funding for FY 1987 should remain at FY 1986 levels, prior to the 4.3 percent automatic spending reduction authorized by the Gramm-Rudman-Hollings Balanced Budget amendment. In addition, we also recommend to the Subcommittee that adequate funding for claims administration expenses under Medicare is necessary in order to avoid hardship to beneficiaries.

A. Older Americans Act/Administration on Aging

The Association recommends a freeze in funding for Older Americans Act programs at the fiscal year 1986 levels, without regard to the 4.3 percent automatic spending reduction under the Gramm-Rudman-Hollings Balanced Budget amendment. This would effectively fund Older Americans Act programs at $701.6 million: the Federal Council on the Aging, $200,000; supportive services and senior centers, $265 million; congregate meals, $336 million; home-delivered meals, $67.9 million; research, training, and demonstration projects, $25 million, and grants to Indian tribes, $7.5 million.

These amounts match the Administration's funding request for AoA/Older Americans Act activities, with the exception of the Title IV research, training, and demonstration program. The Administration requests $12.5 million for Title IV. We urge the Subcommittee to reject this proposal and fund Older Americans Act research, training and demonstration activities at $25 million as was appropriated in FY 1986.

Funding for Title IV has yielded impressive results, despite a modest investment. Some of the most innovative and effective programs in the field of aging have evolved from Older Americans Act demonstrations, including the nutrition program for the elderly, Foster Grandparents, the Retired Senior Volunteer Program, educational television activities, legal services, student training, and improvement of services to minority older persons.

Today, many aged persons are able to live independently in their own homes because of Title III supportive services. The congregate meals program, for example, provides more than just a nutritious meal. It also offers an opportunity for older Americans to meet and talk with others. Moreover, the home-delivered meals program has enabled many older Americans to live independently in their homes, rather than be placed in a nursing home at a much higher public cost.

B. Senior Community Service Employment Program

We further urge that the Title V Senior Community Service

Employment Program be funded at $326 million, the same amount as the Administration recommendation for fiscal year 1987. This also equals the fiscal year 1986 congressional appropriation without regard to the 4.3 percent reduction under the sequestration order.

A $326 million funding level would restore 2,832 positions for Title V, which were cut under the automatic spending reduction. The effect is to provide employment opportunities for 63,784 low-income older Americans in a wide range of useful activities. This takes on added importance now because unemployment jumped by 11 percent for persons 55 or older, from 576,000 in January to 638,000 in March, 1986. Moreover, the number of persons 55 or older in the civilian labor force has declined by 235,000 during the past year, from 15,023,000 in March 1985 to 14,788,000 in March 1986. In marked contrast, the number of individuals 16 to 54 years old in the civilian labor force grew by 2,107,000 during that same period, from 100,312,000 in March 1985 to 102,419,000 in March 1986.

The Senior Community Service Employment Program has been extraordinarily effective for our nation, the older participants, and the communities they serve. The essence of the program is to enable low-income older Americans to help themselves while helping others in their communities.

C. Low Income Home Energy Assistance Program (LIHEAP)

AARP supports funding of the Low Income Home Energy Assistance Program at the FY 1986 level of $2.1 billion, the same level proposed by the Administration. LIHEAP is extremely important to older Americans, who are especially vulnerable to heat stroke and hypothermia. Older consumers spend a higher percentage of their income on home energy than younger people, and those with low incomes must spend disproportionately. Low income households spent some 20% of their income on home energy in 1981, while high income households spent only 3-4 percent.

LIHEAP paid a portion of the heating bills for some 6.8 million households in FY 1985, an estimated 40% of which contained at least one elderly person. Even so, less than a third of all households who are eligible to participate in LIHEAP actually receive benefits, primarily due to chronically inadequate funding. Many states have had to turn away individuals who requested assistance because the program had closed down early with funds exhausted. Thus despite the recent decline in oil prices, the need for energy assistance among low income families remains substantial.

D. Social Services Block Grant (SSBG)

The Association supports funding of the Social Services Block Grant at no less than the current level of $2.7 billion. SSBG provides critically important services that help low income older Americans and others maintain their independence and avoid inappropriate institutionalization. Among services funded by SSBG that keep individuals in their homes as long as possible are homemaker/home chore services, home-delivered meals, and transportation. Adult day care and protective services, also funded by the grant, are designed to prevent or remedy abuse and exploitation of both older adults and children.

The need for social services is expanding as the elderly population grows. Demand has accelerated with the early release of patients from hospitals under the Diagnosis Related Group (DRG) system. If essential services are not available in the community to support such patients upon their discharge from hospitals or skilled nursing care facilities, it is inevitable that greater costs lie ahead.

E. Community Services Block Grant (CSBG)

The Association recommends that the Community Services Block Grant, funded at $368 million this year, be continued at the same level in FY 1987. A GAO study recently found that CSBG funds are used for both services and administration, frequently supporting the administration of other federal programs that could not otherwise fulfill their missions. For instance, the Federal Weatherization Assistance Program has a five percent cap on spending for administration; CSBG funds cover remaining costs.

Services funded by CSBG likewise tend to support other services and often make access to them possible. Without information, referral and outreach -- which represent the most common CSBG-funded activities -- many homebound or isolated older persons would be unaware that emergency food or energy assistance is available in certain areas. Also, transportation funded by CSBG may be the only link between older adults in remote areas and needed medical care. In most cases, according to the GAO, CSBG-funded services complement, rather than duplicate, those supported by the Social Services Block Grant.

F. Medicare Contractor Funding

AARP urges this Subcommittee to approve adequate funding for administrative expense reimbursement to Medicare carriers and intermediaries. Adequate funding is necessary in order to assure expedient and efficient service in the administration of the Medicare program.

Medicare intermediaries and carriers are being placed into a Catch-22 situation. Their funds have been reduced due to the first Gramm-Rudman sequestration; at the same time, the volume of claims for processing and the number of administrative changes in Medicare have been growing. A continuation of inadequate intermediary and carrier funding will produce several problems. First, inadequate funding will create further delays in processing payments for physicians, suppliers, and beneficiaries. The average claims processing time is already increasing dramatically due to recent HCFA directives to create larger claim backlogs. Such delays, if they are allowed to continue, will become a significant disincentive to providers' decision to accept Medicare assignment. If assignment rates drop, beneficiaries will face increased out-of-pocket charges for physician care.

Second, inadequate contractor funding reduces the carrier's ability to perform quality utilization review, a situation which could result in more payment errors and higher costs.

Third, inadequate funding causes services to beneficiaries such as toll-free telephone lines to be curtailed or eliminated.

CONCLUSION

AARP appreciates the Subcommittee's careful consideration of these recommendations and stands ready to work closely with members and staff as you proceed toward markup of a bill for FY 1987.

WEDNESDAY, APRIL 30, 1986.

NATIONAL INSTITUTE ON AGING

WITNESS

DR. DENHAM HARMAN, EXECUTIVE DIRECTOR, AMERICAN AGING ASSOCIATION

Mr. **DWYER**. Our next witness is Dr. Denham Harman.

Dr. **HARMAN**. Mr. Chairman, ladies and gentlemen, my name is Denham Harman, Executive Director of the American Aging Association, Millard Professor of Medicine and Professor of Biochemistry at the University of Nebraska College of Medicine in Omaha, Nebraska.

I appreciate the opportunity on behalf of the American Aging Association to present this testimony.

Life expectancy at birth is the sum of the span of healthy productive life, for example, the functional life span, and of the period of senescence. Life expectancy at birth in the United States rose rapidly from a value of 47.2 years in 1900 to 69.7 years in 1954-1955, and then progressively more slowly to the present value of 74.8 on an advance to a plateau figure of about 75–76 years.

Today, life expectancy is about 10 years less than the maximum average life expectancy at birth of around 85 years, the value to be expected in the absence of overt disease.

Thus, "conquest" of cancer would extend life expectancy about two years, elimination of the cardiovascular diseases approximately five years, and of all the other disorders listed on death certificates, about three years.

Although further increases in average life expectancy from disease oriented biomedical research are not likely, such research should decrease somewhat the average period of senescence.

Biomedical aging research seeks to further increase the functional life span by identifying, and then preventing or slowing, the accumulation of those changes in our bodies with time responsible for the ever-increasing susceptibility to disease and death with advancing age.

Age-related changes are found in all the cells and tissues. They include changes in enzyme activities, formation of age pigment, insoluble material formed largely from unsaturated lipids, amyloid, stronger binding between collagen fibrils, decreased elasticity of the large blood vessels, senile plaques, focal areas of tissue degeneration in the brain.

Also, loss of cells in some areas of the brain, and decreases in the number of mitochondria, the place in our cells when energy released by the O-2 we utilize is converted to a usable form.

Changes such as these, attributed to the aging process, collectively are responsible for the ever-increasing chance of death with advancing age for man, as well as other species.

Preventing, or slowing, changes such as those listed above should decrease susceptibility to disease and death and increase our healthy life span. In doing so, we will put off to a greater age the diseases that kill us, heart attacks, cancer, et cetera, as well as the other problems associated with age such as Alzheimer's disease and senile macular degeneration, a major cause of decreased vision in the elderly.

Through slower aging, a man or woman in the future at age 60 many have the health and vitality of the average 45 to 50-year-old of today.

The conviction that slower aging is a feasible possibility has been growing steadily over the past two decades, due to the gradual accumulation of knowledge of the effects of age on biological systems, and of reasonable hypotheses to account for such changes.

For example, in studies based on one theory of aging, it has been easy to increase the average life span of mice by 20 percent, equivalent to increasing the life span of man from 75 years to 90 years, and to decrease the incidence of disease.

Besides shifting the average life expectancy to higher levels, inhibition of the aging process may also increase the natural human maximum life span to some extent.

It is a reasonable possibility that investigation of the numerous hypotheses already advanced to account for the nature of the aging process, not to mention new ones that are likely to be suggested, will ultimately lead to an understanding of the nature of this process.

Application of that knowledge should almost certainly increase our healthy life span, decrease the period of senescence, and thereby ameliorate the economic and social problems associated with age.

We spend several billions of dollars each year on research on cardiovascular disease and cancer, as well as for treatment of these and other diseases in order to increase our healthy life span.

Prior to the establishment of the National Institute on Aging, funding for aging research was negligible. Yet, aging per se is the process that has almost nullified all attempts to substantially increase our healthy life span for the past three decades.

Even the current National Institute on Aging budget of around $150,000,000 is small when compared to our national yearly expenditure on major diseases. This is especially true since the National Institute on Aging funding figure also includes substantial support for non-biomedical programs.

It was the intent of Congress as expressed by Congressmen Tim L. Carter and Paul G. Rogers on page 275 of the House Congressional Record for May 6, 1974, that the National Institute on Aging should give emphasis to biomedical aging research, and in particular, to determine the cause of aging.

Biomedical aging research is the only part of the umbrella mandate of NIA that is unique to the Institute, and by far the most important.

The major intent of Congress has been largely ignored. Virtually no work is being done to slow the aging process because the vast majority of gerontologists are concerned with the "awesome social consequences of major breakthroughs in aging," as expressed by Robert Butler in his 1974 book, "Why Survive? Being Old in America," and later, by Leonard Hayflick in the January 1982 issue of Executive Health, "At first, I thought it may seem to be a desirable goal to slow the rage of aging. I believe it might be an unmitigated disaster."

Today, essentially all biological, behavioral and social research studies on the aging process are descriptive in nature or related to support programs for older persons.

The concerns of the gerontologists are unwarranted. Life expectancy has increased 25 years since 1900 without producing any social upheavals. Future increases that may be achieved through slower aging are apt to be relatively small, 5 to 15 years, and long in coming, and will probably result in only a few more people living beyond 100 years, the "natural" maximum life span of man.

Slower aging will probably decrease the burden of the over-65 age group on society, even though their numbers will be increased, as this group will have a longer functional life span and a shorter period of senescence.

Time, healthy useful time, is our most valued possession and makes all things possible. The benefits of having more such time to work, to contribute to society, and to do the other things we wish, vastly outweigh any conceivable problems that might arise from slowing the biological process of aging.

The American Aging Association urges the NIA to initiate a major biomedical aging research program focused on determining the biological basis of aging and to apply that knowledge to increasing our span of health life.

The Salk vaccine became available 30 years ago, and still the clamor for more and better iron lungs. Likewise, slowing the aging process will surely decrease the demand on society for more services and better nursing homes for the aged.

The American Aging Association was formed in 1970 in response to the pressing need for more biomedical aging research. AGE is a national lay, scientific health association patterned after the American Heart Association. A highlight of the American Aging Association's annual scientific meeting is the research symposium. A copy of the program for the 1985 meeting is attached.

To help further one of the basic goals of the American Aging Association, to increase the health productive life span, the organization has sponsored the formation of a new medical specialty, clinical gerontology.

The inaugural luncheon of the American College of Clinical Gerontology was held on Friday, March 21, 1986 at the Waldorf Astoria Hotel in New York City.

Clinical gerontologists will utilize a combination of preventive medicine, geriatrics and clinically relevant biomedical aging research.

Individuals will be assessed at appropriate intervals throughout life. Initially, for recommendations regarding medications, diet, exercise, et cetera, measures designed to slow the rate of aging and of disease processes.

Later, for efforts to ameliorate the inevitable deleterious effects of aging and disease and to "cushion" the terminal period of life. These efforts should help each individual maximize their functional life span and minimize the problems associated with age.

The first educational effort of the college will be a two-day series of clinical gerontology lectures. These will be presented in association with the 16th annual meeting of the American Aging Association, September 25–27, 1986, at the Capital Hilton Hotel in Washington, D.C.

In summary, life expectancy at birth, a rough measure of the span of healthy life, is now almost at a plateau value because of the aging process. Slowing this process should increase our healthy life span and diminish the problems associated with age.

We urge Congress to encourage the NIA to initiate a major biomedical aging research program directed to this end to ensure the necessary funds.

Mr. DWYER. Thank you, Doctor.

[The statement of Dr. Harman follows:]

Statement

of

Denham Harman, M.D., Ph.D.

Executive Director

of

The American Aging Association (AGE)

to the

Subcommittee on Labor, Health and Human Services, and Education

of the

U. S. House of Representatives Committee on Appropriations

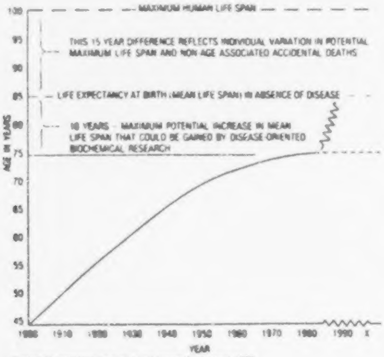
April 30, 1986

Mr. Chairman, Ladies and Gentlemen:

My name is Denham Harman, M.D., Ph.D. I am Executive Director of the American Aging Association (AGE), Millard Professor of Medicine and Professor of Biochemistry at the University of Nebraska College of Medicine in Omaha, Nebraska.

I appreciate the opportunity on behalf of the American Aging Association to amplify my oral testimony before the Labor-HHS-Education Appropriations Subcommittee of the United States House of Representatives on the pressing need to support biomedical aging research.

Life expectancy at birth is the sum of the span of healthy productive life, i.e., the functional life span, and of the period of senescence. Life expectancy at birth in the United States rose rapidly from a value of 47.2 years in 1900 to 69.7 years in 1954-1955 and then progressively more slowly to the present value of 74.8 on an advance to a plateau figure of about 75-76 years as indicated in Figure 1 below.



Average life expectancy at birth in the United States since 1900

Figure 1. Life expectancy at birth in the United States since 1900.

Today life expectancy is about 10 years less than the maximum average life expectancy at birth of around 85 years, the value to be expected in the absence of overt disease. Thus "conquest" of cancer would extend life expectancy about 2 years, elimination of the cardiovascular diseases approximately 5 years, and of all the other disorders listed on death certificates about 3 years. Although further increases in average life expectancy from disease oriented biomedical research are not likely, such research should decrease somewhat the average period of senescence.

Biomedical aging research seeks to further increase the functional life span by identifying, and then preventing or slowing, the accumulation of those changes in our bodies with time responsible for the ever-increasing susceptibility to disease and death with advancing age. Age related changes are found in all the cells and tissues. They include changes in enzyme activities, formation of age pigment - insoluble material formed largely from unsaturated lipids, amyloid, stronger binding between collagen fibrils, decreased elasticity of the large blood vessles, senile plaques - focal areas of tissue degeneration in the brain, loss of cells in some areas of the brain, and decreases in the number of mitochondria - the place in our cells when the energy released by the O_2 we utilize is converted to a useable form. Changes such as these, attributed to the aging process, collectively are responsible for the ever-increasing chance of death with advancing age for man, as well as other species, as shown below in Figure 2.

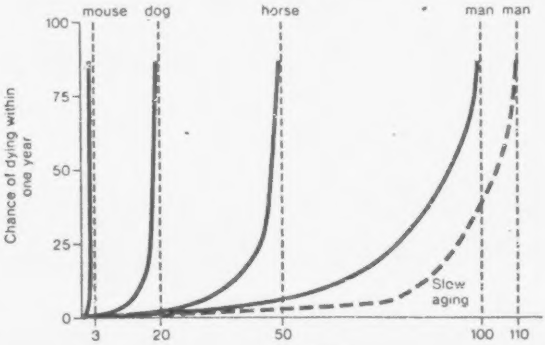


Figure 2. Chance of dying as a function of age for mice, dogs, horse and man as well as the curve that might result if the aging process were slowed in man.

Preventing, or slowing, changes such as those listed above should decrease susceptibility to disease and death and increase our healthy life span. In doing so we will put off to a greater age the diseases that kill us, heart attacks, cancer, etc., as well as the other problems associated with age such as Alzheimer's disease and senile macular degeneration - a major cause of decreased vision in the elderly. Through slower aging, a man or woman in the future at age 60 may have the health and vitality of the average 45-50 year old of today.

The conviction that slower aging is a feasible possibility has been growing steadily over the past two decades, due to the gradual accumulation of knowledge of the effects of age on biological systems, and of reasonable hypotheses to account for such changes. For example, in studies based on one theory of aging, it has been easy to increase the average life span of mice by 20 percent (equivalent to increasing the life span of man from 75 years to 90 years) and to decrease the incidence of disease. Besides shifting the average life expectancy to higher levels, inhibition of the aging process may also increase the natural human maximum life span to some extent.

It is a reasonable possibility that investigation of the numerous hypothesis already advanced to account for the nature of the aging process, not to mention new ones that are likely to be suggested, will ultimately lead to an understanding of the nature of this process. Application of that knowledge should almost certainly increase our healthy life span, decrease the period of senescence, and thereby ameliorate the economic and social problems associated with age.

We spend several billions of dollars each year on research on cardiovascular disease and cancer, as well as for treatment of these and other diseases in order to increase our healthy life span. Prior to the establishment of the National Institute on Aging funding for aging research was negligible. Yet, aging per se is the process that has almost nullified all attempts to substantially increase our healthy life span for the past three decades. Even the current National Institute on Aging budget of around $150.000,000 is small when compared to our national yearly expenditure on major diseases. This is especially true since the National Institute on Aging funding figure also includes substantial support for non-biomedical programs.

It was the intent of Congress as expressed by Congressmen Tim L. Carter and Paul G. Rogers on page 275 of the House Congressional Record for May 6, 1974, that the National Institute on Aging should give emphasis to biomedical aging research, and in particular, to determine the cause of aging. Biomedical aging research is the only part of the umbrella mandate of NIA that is unique to the Institute, and by far the most important. The major intent of Congress has been largely ignored. Virtually no work is being done to slow the aging process because the vast majority of gerontologists are concerned with the "awesome social consequences of major breakthroughs in aging", as expressed by Robert Butler in his 1974 book "Why Survive? Being Old in America", and later, by Leonard Hayflick in the January 1982 issue of Executive Health, "At first thought it may seem to be a desirable goal (to slow the rate of aging). I believe it might be an unmitigated disaster". Today essentially all biological, behavioral and social research studies on the aging process are descriptive in nature or related to support programs for older persons.

The concerns of the gerontologists are unwarrented. Life expectancy has increased 25 years since 1900 without producing any social upheavals. Future increases that may be achieved through slower aging are apt to be relativly small - 5 to 15 years, and long in coming - and will probably result in only a few more people living beyond 100 years, the "natural" maxium life span of man. Slower aging will probably decrease the burden of the over 65 age group on society, even though their numbers will be increased, as this group will have a longer functional life span and a shorter period of senescence. Time, healthy useful time, is our most valued possession and makes all things possible. The benefits of having more such time to work, to contribute to society, and to do the other things we wish, vastly outweight any conceivable problems that might arise from slowing the biological process of aging.

The American Aging Association urges the NIA to initiate a major biomedial aging research program focussed on determining the biological basis of aging and to apply that knowledge to increasing our span of healthy life. The Salk vaccine became available 30 years ago, and stilled the clamor for more and better iron lungs. Likewise, slowing the aging process will surely decrease the demand on society for more services and better nursing homes for the aged.

The American Aging Association (AGE) was formed in 1970 in respouse to the pressing need for more biomedical aging research. AGE is a national lay-scientific health association pattered after the American Heart Association. A highlight of the American Aging Association's annual scientific meeting is the research symposium. A copy of the program for the 1985 meeting is attached.

To help further one of the basic goals of the American Aging Association - to increase the healthy productive life span, the organization has sponsored the formation of a new medical specialty, clinical gerontology. The inaugural luncheon of the American College of Clinical Gerontology was held on Friday, March 21, 1986 at the Waldorf-Astoria Hotel in New York City. Clinical gerontologists will utilize a combination of preventive medicine, geriatrics and clinically relevant biomedical aging research. Individuals will be assessed at appropriate intervals throughout life. Initially, for recommendations regarding medications, diet, exercise, etc. - measures designed to slow the rate of aging and of disease processes. Later, for efforts to ameliorate the inevitable deleterious effects of aging and disease and to "cushion" the terminal period of life. These efforts should help each individual maximize their functional life span and minimize the problems associated with age.

The first educational effort of the College will be a two-day series of clinical gerontology lectures. These will be presented in association with the 16th Annual Meeting of the American Aging Association, September 25-27, 1986, at the Capital Hilton Hotel in Washington, D. C.

In summary, life expectancy at birth, a rough measure of the span of healthy life, is now almost at a plateau value because of the aging process. Slowing this process should increase our healthy life span and diminish the problems associated with age. We urge Congress to encourage the NIA to initiate a major biomedical aging research program directed to this end to ensure the necessary funds.

WEDNESDAY, APRIL 30, 1986.

JOB TRAINING PARTNERSHIP; VOCATIONAL REHABILITATION PROGRAM

WITNESS

SUZAN SHOWN HARJO, EXECUTIVE DIRECTOR, NATIONAL CONGRESS OF AMERICAN INDIANS

Mr. NATCHER. Our next witness is Ms. Suzan Shown Harjo, Executive Director, National Congress of American Indians.

Ms. HARJO. I am with the Cheyenne Nation, and we are from Oklahoma, and Creek Indians, and since 1974, have been the Executive Director of the oldest and largest American Indian membership organization.

We are very concerned about several of the Administration's proposals, and have outlined those concerns in more detail than I will go into now in this presentation, regarding vocational rehabilitation, library services, and the nutrition needs of our Indian elderly; Impact Aid, and the Job Training Partnership Act, and Summer Youth Program.

As a general matter, if Indian people owned what we should and controlled what we owned, we would not need to come before the Congress and say, we need your help, but we do need your help.

We need your help in Indian education. The Indian people have the lowest level of educational attainment of any peoples in the country, and we need your help in funding more for the Summer Youth Program, which has been proposed by the Administration to be cut.

This Summer Youth Program helps us keep our young people occupied in recreational activities, in projects, and our people, unfortunately, have the highest level of unemployment in the Nation, ranging between 50 and 65 percent on most reservations, with the Bureau of Indian Affairs reporting that on 17 medium-sized and larger Indian reservations, right now there is 75 percent unemployment.

Yet, the Administration has sought to cut the JTPA programs by a significant amount, and has proposed to cut the Summer Youth Programs by an even more significant amount, despite the fact that Indian people also have the highest rate of teenage suicide in the Nation.

These situations are helped by these programs. These are vital survival programs for us. They are not satellite programs. They are not luxuries. These are survival programs for us.

The vocational rehabilitation program really does help in Indian country where we have a disproportionate amount of disabling conditions. The highest reported incidence of diabetes in the world, for example, exists on an Indian reservation, and in this country, the Gila River Indian Reservation, and the second highest reported incidence of diabetes in the world exists on the Papago Reservation.

Diabetes in Indian country results in the amputation of limbs, and is not an outpatient disease. It is something that disables our people.

The vocational rehabilitation program does help us. The law itself authorizes up to 1 percent of its funds for tribes, and if that formula had been used, we would receive about 10,000,000 annually, instead of the three-quarters of 1,000,000 we received in 1984; 1,500,000 in 1985 and 1,200,000 in 1986.

We urge you to review our specific recommendations with numbers, in our testimony, and work with our office to do what we can to bring some common sense to these programs for Indian people.

Thank you very much.

Mr. DWYER. Thank you for being there today.

[The statement of Ms. Harjo follows:]

STATEMENT OF SUZAN SHOWN HARJO, EXECUTIVE DIRECTOR, NATIONAL CONGRESS OF AMERICAN INDIANS, FOR FY1987 LABOR-HEALTH AND HUMAN SERVICES-EDUCATION BUDGET BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION, APRIL 30, 1986, WASHINGTON, D.C.

On behalf of the National Congress of American Indians, the nation's oldest and largest membership organization representing American Indian and Alaska Native governments and people, thank you for the opportunity to comment on several appropriations issues under this Subcommittee's jurisdiction.

VOCATIONAL REHABILITATION

While the incidence of disabling conditions among American Indians and Alaska Natives is one and one-half times greater than the rest of the American population, tribal governments have not generally been the recipient of vocational rehabilitation funds. Until last year, only the Navajo Nation had a vocational rehabilitation program. In 1985 two additional tribes - Rocky Boy and Yakima - were able to get vocational rehabilitation funds and begin their own programs.

The current Vocational Rehabilitation law authorizes up to 1% of its funds for tribes. If this authority for tribal funding had been used, tribes would be receiving about $10 million annually, instead of the $750,000 they received in FY1984, $1.5 million in FY1985 and $1.2 million in FY1986. Legislation now moving through the House Education and Labor Committee would require that at least one quarter of one percent of Vocational Rehabilitation monies be reserved for tribes. If this legislation, H.R. 4021, is not signed into law prior to the appropriations bill coming out of Committee, we urge that at least the FY1985 level of $1.5 million be earmarked for tribes.

We would also like to bring to your attention that under the FY1986 Gramm-Rudman sequestration, state Vocational Rehabilitation programs were allowed to be cut by only the amount of COLAs, while Indian Vocational Rehabilitation programs were cut by the full 4.3%. This unfair situation was probably an oversight, but the FY1986 loss to Indian programs sho~~uld be~~ restored and the law corrected for FY1987.

JOB TRAINING PARTNERSHIP ACT

The Administration's proposal for the Native American program authorized in section 401 of the Job Training Partnership Act calls for a FY1987 funding level of $60.1 million, down from a FY1986 level of $62.2 million pre-Gramm-Rudman and $59.5 million after sequestration. The request for the Title II-B Summer Youth Program is very disturbing. The request for that program for FY1987 is $7.8 million, down from a FY1986 level of $12.1 million pre-Gramm-Rudman and $11.6 million after sequestration.

Nearly 200 Indian tribal governments, inter-tribal consortia, native Alaskan groups, off-reservation Indian nonprofit organizations and a native Hawaiian group participate in the Native American JTPA program. Approximately 30,000 Indian workers benefit from this program. In addition, over 130 of these groups, primarily tribal governments, participate as direct grantees under the Title II-B Summer Youth program.

Indian JTPA programs operate in communities suffering from catastrophic levels of unemployment. The last official Bureau of Indian Affairs survey of reservation labor market conditions listed seventeen medium-sized and larger reservations with joblessness rates of 75% or more.

The human toll these conditions take among our people is appalling. Recent outbreak of teen-aged suicide are just one symptom of the problems.

Despite these very difficult economic circumstances, Indian employment and training programs are doing a good job in bringing new skills and new hope to Indian workers.

The only formal evaluation of our program which the Department of Labor ever sponsored found that Indian programs are successful. The evaluation, highlighting Indian programs during the transition from CETA to JTPA, recorded the efforts of grantees to honor the spirit as well as the letter of the law. Emphasis on private sector job linkages, training and performance results were all apparent in the study's findings. We find it strange that Labor Department officials have apparently never communicated the results of this study to your Committee or to other members of the Congress.

Given the monumental unemployment in Indian country we request that at a minimum the JTPA title IV, Section 401 and the Title II-B Summer Youth Program be restored to their FY1986 pre-Gramm-Rudman levels of $62.2 million and $12.1 million respectively.

LIBRARY SERVICES

The Administration has proposed no FY1987 funding for Library Services. The FY1986 level of funding was $127.5 million pre-Gramm-Rudman and $122 million after sequestration.

Libraries in Indian country are few and far between. Even at the tribally-controlled colleges, the library resources are far from adequate. One impediment to tribal colleges obtaining full accreditation is the need for development of adequate libraries. We were very pleased when the Library and Services Construction Act was signed into law in 1984 which included set-aside funding for tribal governments. That was a crucial foot in the door for development of library services in Indian country. We ask you to reject the Administration's proposal for termination of library services and construction, and to protect these programs which are of such potential importance to Indian and Native peoples.

IMPACT AID

We are very concerned with the Administration's FY1987 budget proposal for the construction portion of Impact Aid. The proposal is for $5 million, down from a FY1986 appropriation of $17.5 million pre-Gramm-Rudman and $16.7 million after sequestration. The Department of Education's budget justification reads, "For construction, funding would be reduced from $18 million to $5 million. In districts with federally connected children, a significant level of school construction activities is carried out by the Department of Defense, resulting in a diminished need for funding by the Department of Education." The Department of Education and/or the Office of Management and Budget must have created a new definition for "need". The Construction office of Impact Aid has told us that in FY1985 there was approximately $1 billion in construction requests - $1 billion in requests for a $20 million pot of money. Probably some schools, knowing of the miniscule chance of receiving construction funds, did not bother to make application. In FY1985 $8.5 million of the $20 million in construction funds went to Indian school districts.

The Department of Education is proposing a change in the Impact Aid payment schedule whereby a school would be considered 100% impacted only if 50% or more of their students are federally connected. Under current regulations a school is considered 100% impacted if 20% or more of the students are federally connected. We question whether this is a good idea as most of these schools will not have local revenue to make up the loss of Impact Aid. In addition, the Department of Education has yet to say which schools will be affected and how much money they can expect to lose or how it will interact with the new Local Contribution Rate. We ask the Subcommittee to require a thorough analysis of the consequences of a new payment schedule before the proposal can proceed.

VOLUNTEERS IN SERVICE TO AMERICA (VISTA)

VISTA is the only agency within Action for which the Administration has requested a FY1987 budget cut. VISTA is also the only full time anti-poverty program in Action. Its' focus is exclusively anti-poverty and all its intended beneficiaries are people living in poverty. The FY1987 budget request for VISTA is $17.8 million, down from a FY1986 level of $19.1 million pre-Gramm-Rudman and $18.1 million after sequestration.

The VISTA program has gone from a $36 million budget in 1981 with 5000 volunteers and 900 projects to a 1986 funding level of $18.1 million with 2612 volunteers and 542 projects. While the current law authorizing VISTA specifically mentions assignment of volunteers "in meeting the health, education, welfare or related needs of people living on reservation or federal trust lands", the program, particularly in recent years, has not funded many projects in Indian country. In 1968, for instance, there were 49 Indian VISTA programs with 229 volunteers In 1985 there were only 9 Indian VISTA programs with 52 volunteers, out of a total of 500 projects and 2600 volunteers.

We request that VISTA be funded at its $25 million authorization level, that the Literacy Corps contained in the House VISTA reauthorization legislation, H.R. 4116, be funded at $2 million as authorized in the bill, and that VISTA be required to more actively recruit for projects in Indian country. We like the change made in VISTA in recent years whereby volunteers are recruited locally. Recruitment of non-Indian volunteers for reservation-based programs has often proved unsuccessful.

GRANTS TO TRIBES FOR NUTRITION AND OTHER SERVICES

The Administration is requesting $7.5 million in FY1987 for Grants to Tribes for Nutrition and Other Services, a program of great value to the rural elderly Indian people on reservations. In the past few years the number of tribes eligible for this program has nearly doubled, while the funding has gone up only about one quarter. While we welcome expanded tribal eligibility, we also feel that an appropriation of $9 or $10 million is needed to keep pace with the increased usage of the program. Currently 127 tribes are eligible for this program.

Mr. DWYER. This committee will stand in recess until 2 p.m. this afternoon.

AFTERNOON SESSION

WEDNESDAY, APRIL 30, 1986.

TRADE ADJUSTMENT ASSISTANCE AND LIBRARY ASSISTANCE

WITNESS

HON. JAMES L. OBERSTAR, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

Mr. NATCHER. Our first witness this afternoon is our friend and colleague from Minnesota, James L. Oberstar. Come around and have a seat there at the table.

We are glad to have you, and on the record, I want to say this, Mr. Conte, to our friend, Jim Oberstar, when we bring our bill out, Jim Oberstar helps us every year, and I want you to know that we appreciate it.

This bill is a right difficult bill from the standpoint of marking it up, taking it through the House, to the Senate, down to the White House; you always help us, and we will be glad to listen to you.

Mr. OBERSTAR. Thank you very much, Mr. Chairman.

Now is the time to make my case.

Mr. CONTE. That is the truth, though. We have a lot of colleagues that come up here and testify for something in this bill, and then they turn around and vote against us. We have a lot of them, but not Jim.

Mr. NATCHER. Not Jim Oberstar.

Mr. OBERSTAR. You do your work on both sides in a bipartisan way on this legislation, and you fashion a bill that is responsible; I have never voted for any of those across-the-board cuts, to reduce any of the funding, because the budget you handle is one that touches most directly and in the most intimate way the lives of people in this country.

For the record, Christine Donohue of my staff has helped in the preparation of this statement, and I would like to enter the statement, with the committee's approval, in the record and summarize the two key elements that I want to address:

The trade adjustment assistance funding and library assistance.

When we began the process of opening America's trade doors with the Kennedy round of negotiations under GATT in the early sixties, we knew there was going to be dislocation in the marketplace from goods that were underpriced, produced in government-supported factories overseas; and that American jobs would be lost.

And we envisioned a program of providing some offset for the job loss. Trade adjustment assistance was a long time in coming, and finally passed in the form we have today, in 1974.

And yet, this Administration has sought to eliminate the trade adjustment assistance funding. Now, northeastern Minnesota, a resource-dependent district, abundant in iron ore, and the only thing we can do with it is to sell it to the steel mills. This industry has been devastated every bit as much as the shoe industry, and textiles and other sectors of the economy that have been opened to unfair foreign-produced products.

The people who have lost their jobs in my district have had to seek training for new skills, either to move away or for the few new industries, smaller size, smaller job numbers that have relocated or have sprung up in our district.

Four years ago, the gross regional product of northeastern Minnesota was based on taconite, 55 percent of total goods and services. We had 15,000 workers, $900,000 in goods and services purchased by the taconite industry.

Today, there are 6,500 jobs, $180,000,000 payroll, buying less than half the number of goods and services, and 15,000 people have moved out of one county in my district, because they don't want tc be on welfare, and they can't find other jobs, and now they have been denied the opportunity for training under the trade adjustment program so that they can acquire the skills that the President is telling them, go someplace else and find work.

There are jobs around this country, but if you don't have a skill, you can't get a job. The $28,000,000 that was appropriated, that this committee made available for the current fiscal year, the Administration recommends zeroing out.

I plead with you to restore those funds. Vocational, technical schools in northern Minnesota, the finest in the country, they are new, up to date, and they have kept pace with technology, and they are full.

People are enrolling, but as they see those funds cut, they cannot go to school. They can't get a job. There is not going to be any future for them, so please do all that you can to restore—that is the very least that we can do, Mr. Chairman, training, provide opportunity for new skills.

In Europe after the war, when the coal and steel community had been devastated and Europe was rebuilding, they went through a transition period in which some factories were closed, mines shut down. I was a student in Europe at the time and studied this, followed it since, provided training, full salaries, total relocation assistance.

And they rebuilt the coal and steel industry in Europe to a $50,000,000,000 rival of the United States, and they had no strikes or riots or uprisings or communist influence as a result of it.

We should learn our lesson from Europe and at least do for our workers what other countries have done for theirs.

The library program, Mr. Chairman, you listened with great intensity and very thoughtful in receiving some documents five years ago, when the Administration first proposed eliminating the library assistance program.

We were starting the downslide in the iron ore mining industry in the City of Duluth because of the port situation. I told the story of how the central library in Duluth had a toy lending program, and every weekend, the toys were lent out completely, because the people didn't have money to go out and buy toys.

They had set up programs to teach unemployed people how to write a resume, now to circulate that resume, and the library had set up diaper changing tables for fathers who were coming in with their children, because the wife was working, and they were taking care of infants, in the library.

Well, that library is continuing to thrive. We have a regional, seven-county regional library service, 100,000 people a year benefit from the regional bookmobile and library service.

This is an economic development tool. Small businesses come into the libraries to learn how to expand their operations. Unemployed people come in to learn where to look for jobs, how to write resumes, how to get technical assistance, improve their employability.

I plead with you, on two levels, standard services that libraries supply are vital in a free and intelligent society, but they are also an economic development tool vital to areas suffering from economic distress.

Restore those funds. It is an investment in the future. Thank you, Mr. Chairman.

Mr. NATCHER. Mr. Oberstar, thank you for your appearance before our committee. We appreciate your assistance. When we bring our bill out. You can come back and see us any time.

Thank you very much.

[The statement of Mr. Oberstar follows:]

STATEMENT OF THE HONORABLE JAMES L. OBERSTAR
OF MINNESOTA
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
APRIL 30, 1986

MR. OBERSTAR. MR. CHAIRMAN, I welcome this opportunity to appear before the Subcommittee and discuss the need to preserve the Trade Adjustment Assistance Program. As the nation's manufacturing sector continues to be plagued by U.S. noncompetitiveness with foreign goods, the need to assist our workers who find themselves out of work, through no fault of their own, continues to grow.

I will also discuss the need to preserve, and even develop our nation's library resources. Not only our students, but all library-users, which I suspect includes a majority of Members of this Subcommittee, would suffer under the library services scenario outlined in the President's FY'87 budget.

The importance of this hearing to my Eighth Congressional District in Minnesota cannot be underestimated. We are a mining region. We produce iron ore and make it into taconite pellets which then are shipped to lower lakeports to be made into steel.

Until 1980, our mines flourished -- people were confident about themselves and about the future. At its height, theiron mining and processing industry accounted for 55% of the regional economy of northeastern Minnesota. In 1981 it purchased $900 million in goods and services from 2,000 Minnesota businesses and employed 15,000 people with a $400 million payroll. Last year, that same industry employed about 6,500 people with a payroll of less than $180 million.

It was as if all of a sudden someone turned the lights out on our boom, forcing us to live under the dark skies of unemployment, plant closings and economic uncertainty.

Increasingly in the last one or two years, we have made progress toward diversifying our economy and getting back on the road to recovery.

An important factor in that recovery has been the Trade Adjustment Assistance program. TAA is relied upon to give economic and retraining assistance to individuals who otherwise would have no hope at all. TAA has enabled people to maintain their integrity during times of emotional and economic upheaval.

But the issue extends much deeper than the need for TAA funds -- it is a **right** of every worker who has lost his job due to changes in the domestic economy, caused by America's international trade policy allowing more foreign goods in the domestic marketplace, to receive some sort of compensation.

In 1962, the Kennedy Administration, participating in the General Agreement on Tariffs and Trade, opened America's trade doors to the world. At that time, negotiators realized that there would be dislocation in the domestic economy as a result of reducing tariffs, quotas, and other trade barriers.

In an attempt to minimize the effects of this dislocation, the 1974 Trade Adjustment Act was enacted. This Act was passed to assist workers and industries -- principally workers, to adjust to the world of dislocation. The intent of the act was clear, and to the extent that a degree of dislocation was inevitable, it was a fair proposal.

Since that time, and especially in the last six years, we have seen a gross betrayal of the worker-assistance provisions of the bill. The United States has continued to open its doors to unfairly subsidized imports, while simultaneously refusing to demand that the same treatment be afforded our goods abroad. We have, in effect, stood by and watched our nation accept an open door trade policy that only swings one way, and hits us hard as it slams shut on our goods.

It is a tragedy that the Reagan Administration, and the Carter Administration before it, permitted our domestic industries to deteriorate to the point that we have a difficult time competing. Those Members of the Subcommittee who have travelled to the Mesabi Range in northeastern Minnesota will know that I do not exaggerate when I state that the decline in the steel industry has devastated local economies.

But we know that there is a way out of all of this, and that we can't get there from here unless we are in partnership with the federal government. Every TAA dollar spent in my District has gone, in some manner, to help diversify our economy.

And it's working. We are developing our timber industry as quickly as is environmentally safe. Hibbing, Minnesota is the home of an Industrial Wood Products Park, which eventually will house all wood product industries. I take special delight in the Hibbing Chopsticks Factory, which is under contract to produce more than one **billion** chopsticks for export to Japan.

Last weekend we broke ground for the Lake Superior Paper Mill in Duluth, which when operating at full capacity will employ 600 people, including 300 pulpcutters and 300 in-plant workers. Vocational schools in the area have added related courses to their curriculums to help train people to fill the 300 managerial positions the mill will create.

Although the State of Minnesota has been a leader in implementing training programs for our dislocated workers, the federal partnership provided by TAA is critical to maintaining our commitment to each displaced worker in need of retraining.

Expansion of our tourism industry will also involve new skills. We are blessed with an abundance of natural resources which serve as the basis of our growing tourism industry. The Boundary Waters Canoe Area Wilderness, the Superior National Forest, Voyageur's National Park, the Disabled Veterans Wilderness Retreat, the Chippewa National Forest, and Grand Portage National Monument are some of the federal and state recreation lands in our region. This is in addition to thousands of lakes stocked with the world's finest walleye, northern pike and crappie.

Community and regional development commissions have sprung up across the region and formulated plans to enhance our tourism industry.

So we are on the right track back to economic stability, but we still have a very long way to go. And the need for TAA dollars remains critical at a time we continue to be plagued by an Administration determined to cut TAA programs.

Workers in my District deserve better than this. They have endured lay-offs, very often with little to no advance notice; they have watched friends pack up and move away; they have seen school's close down; and they have watched the value of their homes plummet.

Northeastern Minnesota has traditionally been a region where children remain at home, and never see much sense in moving elsewhere. It is a beautiful area, where up until recently, a good future was possible for every hardworking person. But I can't remember the last time a young person expressed to me his plans to remain on the Mesabi Range. Realistically, it just doesn't make sense for a young person to stake his future on our region, especially at a time when the Administration continues to turn its back on us.

But there is hope, and a part of that hope is TAA funding. TAA has enabled our displaced workers to make ends meet while searching for new jobs. It has enabled them to learn the skills that will be vital to the diversification of our economy. And it has helped them to find new jobs.

The Job Corps is another job training program which has played an important role in the region. From 1981 through 1985, 321 individuals from my District have participated in the Job Corps. The placement rates for these young people have kept up with the national average. The Job Corps has helped these people secure jobs -- and in some instances to move into management positions. I urge the Subcommittee to continue Job Corps funding at FY'86 level.

LIBRARIES -$129 M

I am also here today on behalf of our country's public libraries, to request that funding for library services programs for fiscal year 1987 be maintained at the current services level.

A little over $2 million of the funds Minnesota spent on public library services in FY'85 came from Federal Library Services and Construction Act funding. This is a small, but very important part of ~~the~~ State's total budget for library services. Federal funds support a variety of services in Minnesota, including bookmobile service on Indian reservations, library resources for the blind and physically handicapped, library services for institutionalized persons and public library construction.

Libraries across the country saw the postal rates for mailing books go up twice **this year** -- in January and again in March. Six regional public library systems and two county libraries operate books-by-mail service for persons who are homebound or living in remote areas in Minnesota. Over 100,000 rural residents receive books directly through the Mail-A-Book service in the Arrowhead Library Syustem in my Congressional

District in northeastern Minnesota. The increase in postal rates has placed an additional burden on the already limited budgets of public libraries.

In addition, during the last session of the Minnesota State Legislature, $500,000 was cut from the State's budget for library services.

Since the Library Services and Construction Act was passed in 1956, tremendous progress has been made in helping States establish, extend, and improve public library services. But in Minnesota more than 90,000 citizens who live in rural areas still have no library service, and in many instances, what service does exist is inadequate to many of the handicapped, institutionalized, and minority citizens.

Federal funding for library services is still important. I urge that funding for fiscal year 1987 be maintained at the current services level.

Again I want to thank you, Mr. Chairman, for your hard work and persistence in recognizing the importance of our TAA and library programs. It is unfortunate that the Administration will not address the needs of the beneficiaries of these programs. But my constituents and I find comfort in knowing of the Subcommittee's support.

WEDNESDAY, APRIL 30, 1986.

REHABILITATION PROGRAMS

WITNESS

DR. BRUCE GANS, AMERICAN ACADEMY OF PHYSICAL MEDICINE AND CONGRESS OF REHABILITATION MEDICINE

Mr. NATCHER. Our next witness is Dr. Gans. Come around, Mr. Gans, we will be pleased to hear from you.

Dr. GANS. Mr. Chairman, I am Bruce Gans, M.D., Chairman of the Department of Physical Medicine and Rehabilitation at Tufts University in Boston, and Director of both the Medical Rehabilitation Research and Training Center, and the Rehabilitation Engineering Center, and I am here testifying on appropriations for rehabilitation research supported by the National Institute of Handicapped Research, in the Department of Education, and the professional training supported by the Rehabilitation Services Administration.

I would like to comment about the services by the National Institutes of Health. I am testifying on behalf of the American Academy of Physical Medicine and Rehabilitation, the American Congress of Rehabilitation Medicine and the Association of Academic Psychiatrists.

The NIHR was created by the Congress to develop the knowledge needed to improve rehabilitation services and to address the national problems of disability.

Current estimates are that more than 36,000,000 Americans are disabled, and that the aggregate costs of disability are approaching 8 percent of the Nation's Gross National Product.

The prevalence of disability continues to grow as our population's average age increases and as we experience advances in acute care medicine that can sustain life, but not assure life without disability.

Some NIHR achievements are important to know. There is reason to be proud of the problem solutions and new service capabilities that have resulted from NIHR-sponsored research.

The successes include: Better methods for preventing costly medical complications in patients with severe physical impairments such as spinal cord injury, head injuries, stroke and amputation.

New methods of quantifying disability so that the outcomes of rehabilitation programs can be rigorously evaluated.

New ways of securing the private sector's participation in the vocational rehabilitation of severely disabled persons.

Ongoing research that is supported by the NIHR holds the promise for future achievements that are no less significant: The Research and Training Center at my institution has performed research to identify preventable factors leading to the rehospitalization of chronically disabled patients who have been discharged from medical rehabilitation.

It is important to understand the reasons for rehospitalization since this disrupts the individual's work or schooling, and is the single most costly aspect of follow-up care.

Tufts is collaborating with others in an information collection study about serious trauma occurring in childhood, including 31 collaborating institutions in the United States and Canada.

These data will allow us to understand and to reduce the disabling consequences of serious childhood injuries.

The Research and Training Center at Northwestern University is demonstrating the potential benefit of new computer technology for improving difficulties that patients with head injury or stroke may have in logical thinking or memory.

These computerized treatment methods may be highly individualized for each patient; they provide sensitive quantitative indications of patient progress, and they represent tireless instructors that can substitute effectively for the more costly time efforts of therapists.

Achievements such as these are being accomplished with an annual NIHR budget that, in inflation-corrected dollars, is only one-half of the rehabilitation research budget for 1969. The current total NIHR budget represents little more than $1 expended for each disabled person in this country.

The aggregate investment annually by all Federal agencies in rehabilitation research is less than .2 of 1 percent of the estimated total yearly costs of disability.

In the health care area generally, approximately 3.5 percent of total health care expenditures are devoted to research and development. The research funds available to address the problems of disability in this country are less than a tenth of what is needed and appropriate.

The current NIHR budget, assuming Gramm-Rudman reductions, is $42,000,000. The original 1985 appropriation was $39,000,000; the fiscal year 1986 original appropriation $44,000,000; and the President's 1987 budget, $39,000,000.

Even in fiscal year 1985 and fiscal year 1986, with approximately 10 percent increases, the programs of NIHR have fallen to levels far below fiscal year 1984. Centers are being continued, but most have not received increases in funding since receiving their original grant award three years ago.

There were 47 new field initiated, individual research grants in fiscal year 1984, but only 20, including a subset called innovative grants, in fiscal year 1985, and probably 30 this year.

A critically needed new research training program was to have been funded at $1,000,000 in fiscal year 1985, but it just now beginning in fiscal year 1986 at only $300,000. To make matters obviously worse, the President's budget for fiscal year 1987 of $39,000,000 only funds continuation grants, and with no increase in grant size between 1986 and 1987.

The NIH routinely supports individual research grants and centers in their continuation years at levels modestly higher than prior years depending upon peer review approval.

We recommend a budget of at least $49,000,000 for fiscal year 1987 for NIHR. Such a budget will just continue fiscal year 1984 levels of effort and those specified by Congress for fiscal year 1985 and fiscal year 1986.

It would continue all existing grants and allow for a current services increase for fiscal year 1987 of $2,000,000 to $3,000,000.

As noted, most center grants have received no increases for two years, and they should be increased to account for increased costs.

The recommended budget for fiscal year 1987 would include $5,000,000 to fund 47 new field initiated and innovative grants, the level funded in fiscal year 1984 and urged in fiscal year 1985 and fiscal year 1986 by this committee, and the level directed by the recent House report from the Education and Labor Committee regarding the 1986 Rehabilitation Act Amendments.

This budget would also fund research training at $1,000,000 for new traineeships, the level recommended in the original fiscal year 1986 budget. This $1,000,000 would fund about 10 to 12 institutional training awards. Only three are likely to be started this year.

Finally, a $49,000,000 budget would enable NIHR to undertake a much-needed initiative in head injury rehabilitation research. The research community, consumer community and the NIHR all agree that head injury research in rehabilitative care is in need of expansion.

Research to improve rehabilitation services to the head injured should be a top priority. A limited amount of work is being done at two research and training centers and it is encouraging.

The initiative we support provides support for six or more model head injury service systems which would support research on individual treatment interventions, such as those dealing with improved cognitive ability.

This budget should be modeled after the existing regional spinal cord injury center program which has been very successful. At least $2,000,000 is necessary to launch this initiative.

In the fiscal year 1986 appropriation bill report, this committee urged NIH to report on the extent of rehabilitation related research supported by the various NIH Institutes and programs, and also on future plans for research in this field.

We would hope that NIH would continue the level of effort indicated by this report, and focus its activity even more on the improved physical function of individuals with severe physical disabilities such as stroke, arthritis, spinal injury, head injury, chronic pain and multiple sclerosis.

We support the budget request of the Ad Hoc Coalition for Biomedical Research of $6,100,000,000 for NIH as a whole, and we strongly support the recommendations of the Arthritis Institute Coalition of $138,000,000 for that Institute.

It is very important to assure a significant increase of money for this new Institute, which has been working very closely with the rehabilitation medicine community for the last few years.

Finally, we recommend the levels set forth in the attached report of the National Rehabilitation Coalition for the programs of the Rehabilitation Services Administration, including, of particular importance to us, $32,000,000 for professional training.

Thank you very much.

Mr. **Natcher**. Thank you very much, Dr. Gans.

[The statement of Dr. Gans follows:]

TESTIMONY

OF

BRUCE GANS, M.D.

FOR THE

AMERICAN ACADEMY OF

PHYSICAL MEDICINE AND

REHABILITATION ET AL

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON

APPROPRIATIONS FOR THE DEPARTMENTS OF

HHS, EDUCATION AND LABOR

APRIL 30, 1986

Mr. Chairman:

I am Bruce Gans M.D., Chairman of the Department of Physical Medicine and Rehabilitation at Tufts University Medical School in Boston and Director of both a Rehabilitation Research & Training Center and Rehabilitation Engineering Center. I am testifying on appropriations for rehabilitation research supported by the National Institute of Handicapped Research (NIHR) and the National Institutes of Health and professional training supported by the Rehabilitioan Services Administration. I am testifying on behalf of the American Academy of Physical Medicine and Rehabilitation, the American Congress of Rehabilitation Medicine, and the Association of Academic Physiatrists

The "NIHR Budget". The NIHR was created by the Congress to develop the knowledge needed to improve rehabilitation services and to address the national problem of disability. Currently estimates are that more than 36 million Americans are disabled, and that the aggregate costs of disability are approaching 8% of tha nation's gross national product. The prevalence of disability continues to grow as our population's average age increases and as we experience the miracles of acute care medicine that can sustain life, but not assure life without disability.

The scope of disability in this country is one fact; another fact is the marked insufficiency of rehabilitation services to promote the independence and productivity of persons with disability. Public policy options to dealing with this disparity are threefold: 1)spend more money on expanding currently envisionable services 2) hold expenditures for rehabilitation services constant and fall further behind, or 3) learn how to get better services outcomes for each dollar spent. That, Mr. Chairman, is precisely the purpose of research sponsored by NIHR. Of course, NIHR is not the only research funding agency dealing with disability and with improving rehabilitation services. The National Institutes of Health support a good deal of related work, but it tends to be fundamental research which is not directly targeted on improved services for disabled persons.

Some NIHR Achievements. There is reason to be proud of the problem solutions and new service capabilities that have resulted from NIHR-sponsored research. The successes include:

- Better methods for preventing costly medical complications in patients with severe physical impairments such as spinal cord injury, stroke, and amputation;

- New methods of quantifying disability so that the outcomes of rehabilitation programs can be rigorously evaluated.

- New ways of securing the private sector's participation in the vocational rehabilitation of severely disabled persons.

Ongoing research supported by NIHR holds promise for future achievements no less significant. The Research and Training Center at the Tufts-New England Medical Center has established a data base needed to identify factors leading to the rehospitalization of chronically disabled patients who have bee discharged from medical rehabilitation. It is important to understand the reasons for rehospitalization since it disrupts the individual's work or schooling and is the single most costly aspect of follow-up care.

The Research and Training Center at Northwestern University is demonstrating the potentiality of new computer technology for improving difficulties that patients with head injury or stroke may have in logical thinking or memory. Such computerized treatment methods can be highly individualized for each patient; they provide sensitive quantitative indications of patient progress, and they represent tireless instructors that can substitute effectively for the costly time-effort of therapists.

At the Research and Training Center at Baylor College of Medicine and The Institute for Rehabilitation and Research, researchers are exploring the use of implanted miniaturized electronic systems to eliminate involuntary limb movements ("spasticity") exhibited by some persons with spinal cord injury. Such involuntary movements interfere with walking which otherwise may be possible or with a variety of daily activities by wheelchair users. When the stimulation is effective , it is possible to avoid customary destructive surgical procedures or medications whose side effects decrease the individual's alertness in school or work.

A project being conducted at the Research and Training Center at the University of Connecticut Health Care exemplifies an anticipatory intervention intended to forestall the development of disability. A systematic evaluation is being made of supportive consultation for parents of infants who are at high risk for developing disability. This intervention is expected to reduce family stress associated with newborn intensive care and with the homecoming of high risk infants and to produce gains in infant development and adaptive functioning.

Achievements like those that have been cited are being accomplished with an annual NIHR budget that, in inflation-corrected dollars, is one-half of the rehabilitation resarch budget for 1969. The current NIHR budget represents only a little more than one dollar for each disabled person in this country. The aggregate investment annually by all federal agencies in rehabilitation research is less than .2 of 1% of the estimated total yearly costs of disability. In the health care area generally, approximately 3.5% of total health care costs is devoted to research and development. In short, research funds available to address the problem of disability in this country are an order of magnitude less than is appropriate.

The NIHR now has a new Director, David Gray,1 Ph.D, formerly at the National Institutes of Health as a program manager in the NICHHD. It has a new Deputy Director, Alton Hodges Ph.D, formerly a Senior Fellow at the Institute of Medicine. We are very pleased with these appointments and with the relationship between the NIHR leadership and the scientific community.

The new leadership is dedicated to further improving the peer review system, to supporting field initiated individual research grants and research training and to working closely with sister agencies, particulary NIH. However, the lack of resources available will, in our opinion, be fatal to these well intended, creative purposes.

The current NIHR budget, assuming Gramm-Rudman reductions, is $42 million. The original '85 appropriation was $39 million the FY86 original appropriation $44 million and the President's '87 budget $39 million.

Even in FY'85 and FY'86, with approximately 10% increases, the programs of NIHR have fallen to levels of effort below FY'84. Centers are being continued but most all have not received increases at all since receiving their original grants three years ago. There were 47 new Field Initiated, Individual Research Grants in FY'84 but only 20 including a subset called Innovative grants in FY'85 and probably 30 this year. A new Research Training program was to have been funded at $1 million in FY'85 and is just beginning in FY'86 but at $300,000. To make matters obviously worse, the President's budget for FY'87 of $39M only funds continuation grants and with no increase in grant size between '86 and '87. The NIH, routinely supports individual research grants and centers in their continuation years at levels modestly higher than prior years depending upon peer review approval.

We recommend a budget of $49 million for FY'87 for NIHR. Such a budget is essentially a budget intended to continue FY'84 levels of effort and those specified by Congress for FY'85 and FY'86. It would continue all existing grants and allow for a current services increase for FY'87 of $2 million to $3 million. As noted, most Center grants have received no increases for 2 years and should be increased to account for increased costs. The recommended budget for FY'87 would include $5 million to fund 47 new Field Initiated and Innovative grants, the level funded in FY'84 and urged in FY'85 and FY'86 by this Committee and the level directed by the recent House Report from the Education and Labor Committee regarding the 1986 Rehabilitation Act Amendments. This budget would fund research training at $1 million for new traineeships, the level recommended in the original FY'86 NIHR budget. $1 million would fund about 10 to 12 institutional training awards. Only 3 are likely to be started this year.

Finally a $49 million budget would enable NIHR to undertake a much needed initiative in head injury research. The research community, consumer community and the NIHR all agree that head injury research in rehabilitative care is ripe for expansion if funding ever were available and that the area of improved services to the head injured should be a top priority. A limited amount of work is being done at 2 R&T Centers and it is encouraging. The initiative we recommend, after considerable consultation within the research community and with consumers, involves support of 6 or more model head injury service systems which would also support expanded research on individual treatment interventions, such as those dealing with improved cognitive ability. This approach is modeled on the existing spinal injury research and service delivery program which has been very successful. At least $1 million to $2 million is necessary for this initiative.

NIH BUDGET FOR REHABILITATION RELATED RESEARCH

In the FY'86 appropriation bill report this Committee urged NIH to report on the extent of rehabilitation related research supported by the various NIH Institutes and programs and on future plans for research in this field. The report is very informative and has assisted the research committees of our three organizations to begin a potentially useful dialogue with NIH. The NIH leadership has been exceptionally receptive to discussing with us methods of further participation by researchers in the rehabilitation field on study sections and advisory councils. While we believe that the figures indicated relative to NIH research in rehabilitation are too high, the difference depends on the broadness of the definition of rehabilitation research.

Existing science related to rehabilitation is being supported by a number of Institutes in NIH,1 particularly the Aging Institute, the Arthritis Institute and the Neurology Institute. It includes: research regarding urinary tract infections and hip fracture consequences from falls supported by NIA; research regarding the appropriate mechanical environment for fracture healing and a portable stimulator for treatment of hip disorders by NIAMS; research on nueral prosthesis and spasticity in the brain injured by NINCDS; research regarding speech and language development among the retarded by the

NICHHD; reseacrh regarding the management of chronic pain and research regarding the development of adaptive machines to measure and rehabilitate muscular deficits from trauma or disuse by the NIGMS.

We would hope that NIH would continue the level of effort indicated by this report and focus it's activity even more on the improved physical function of individuals with severe physical disabilities such as stroke, arthritis, spinal injury, head injury, chronic pain, multiple sclerosis. We support the budget request of the Ad Hoc Coalition for Biomedical Research of 6.1 billion for NIH as a whole and we strongly support the recommendations of the Arthritis Institute Coalition of $138 million for that Institute. It is very important to assure a significant increase of money for this new Institute which has been working very closely with the rehabilitation medicine community for the last few years.

We would urge the Committee to stress the importance of the NIH commitment to medical rehabilitation research and indicate the continued need for an NIH wide report on research activity in this field. We would also appreciate having the Committee indicate it's support for the NIH initiative to assist in providing more participation on existing study sections by the rehabilition research community.

Rehabilitation Training

Finally , we recommend the levels set forth in the attached report of the National Rehabilitation Coalition for the programs of the Rehabilitation Services Administration including, of particular importance to us, $32 million for professional training.

0096D/

WEDNESDAY, APRIL 30, 1986.

REHABILITATION PROGRAMS

WITNESSES

MARILYN SPIVACK, EXECUTIVE DIRECTOR, NATIONAL HEAD INJURY FOUNDATION

MARTIN L. SPIVACK, PAST PRESIDENT

ALICE M. DEMICHELIS, LEGISLATIVE LIAISON

ROBERT DEMICHELIS

Mr. NATCHER. Our next witnesses are Mr. and Mrs. Spivack.

Ms. SPIVACK. Mr. Chairman, I have with me Mrs. Alice Demichelis, who is a parent of a head-injured young man, Robert Demichelis. And Mrs. Demichelis is our Legislative Liaison here in Washington.

My name is Marilyn Price Spivack, co-founder and Executive Director of the National Head Injury Foundation. First, thank you all for your legislative language of 1984 and again in 1985. It has truly helped gain attention for our population; this year, appropriations are desperately needed to turn language into implementation.

I am proud to announce that only two weeks ago, we held our first NHIF Convention here in Washington, D.C. We made 116 Congressional calls. Representatives Conte and Dicks were wonderful luncheon speakers.

They, as well as many on this committee, have been of great assistance in helping us make significant strides. Our membership expressed deep appreciation.

I will remind this committee that my own daughter, Debby, was severely brain injured in 1975. I am still a mother searching and trying to build a lifelong plan for our beautiful 26-year-old daughter, a young woman who clearly remembers who she was and what she might have been.

Since 1980, I represent tens of thousands of Debbys. Each year, we add 50,000 young people to swelling numbers of victims of severe THI. Annually, 500,000 to 700,000 are hospitalized, left with minor to moderate impairments; most need services for a period of time.

More young people are lost to head trauma than to all our wars. We lose more people than in all our wars.

Again, we come to you for your help to appropriate the funding requests for fiscal year 1987 in all programs for people with disabilities as recommended by the National Rehabilitation Coalition and the Consortium for Citizens with Developmental Disabilities.

Without increased funding, there is hardly hope for the large population we have just begun to identify, who have had no recognition, therefore no services, and who need them urgently.

The state-of-the-art in head injury rehabilitation is just developing, therefore, research and training are critical.

To be specific, we strongly urge continued and expended research under NINCDS. The outlook is basic neuroscience is quite optimistic, but cutbacks will cost us dearly over the future if we do not seek to lessen the degree of disability caused by central nervous system trauma. We need more, not less.

We support the funding recommendations of the National Committee on Research.

We also are in full support of the $49,000,000 recommended budget for NIHR. Last year, you directed NIHR to make THI a priority area this coming year. The opportunities to enhance research in this case may indeed turn a developing state of the art into a state of the practice, which will ultimately change the future for this generation of persons with THI.

Some neurosurgeons and rehabilitationists now recognize appropriate rehabilitation even years after the injury can increase the level of function and productivity, thereby providing an enhanced quality of life and reduce long-term costs.

Deprivation of rehabilitation clearly causes regression, further tragedies and creates higher costs to family and society in both human and economic terms. I stand witness to that as I travel across this country meeting survivors, families and caring professions.

I just came back from Lexington, Kentucky, and it is a beautiful place to be, but not if you have a head injury. We are pleased that a Kentucky Head Injury Foundation is in the process of being formed. The Administration at Cardinal Hill is organizing a statewide effort for us.

Last year, I told you it was difficult to be head-injured person in Kentucky. I have been there and it is very beautiful, but there is a dearth of knowledge, programs and services. Kentucky is one of many States still not ready to meet the need.

I have been to most of your home States. There is a real need in this area for training medical and rehab professionals in head trauma care and rehabilitation, and for developing model systems of care. We have worked closely with NIHR, and have stated our specific needs. We support the $49,000,000 request.

A year ago, May 14, the day of our testimony, we also signed the NHIF/OSERS Agreement. That agreement has already become a viable working document producing results in training, dissemination of information and planning service systems at national and State levels.

It has been replicated in six States and in negotiation stages in 18 others with NHIF State associations. Without sufficient Federal funds in programs under OSERS, the agreement may wither.

We do not think this was the intent of this committee, who helped make that agreement a reality by influencing the 1985 report to Congress from RSA and related agencies. We support funding at $1,379,400,000 for the basic State rehabilitation services.

The 1985 report published by the National Academy Press, "Injury in America," stated that injury is the last major plague of our young. THI accounts for a major percent of injuries, yet in 1983, only $112,000,000 was spent on injury-related research, plus 4,000,000 spent on head trauma, despite the fact that we lose 4,100,000 productive lives annually to injury.

So, we would ask why this government, so rich in resources, is not taking immediate and dramatic steps to control, decrease injuries and create systems of eligibility and funding to rehabilitative victims of THI, a plague that robs us of our children and young adults.

In closing, the NHIF makes two major requests of this committee.

One, to appropriate funding as recommended by CCDD and NRC to all agencies that serve people with disabilities.

Two, to include language and allocations that would urge the appropriate agencies to identify traumatic head injuries as a specific diagnostic category for reasons outlined in our submitted testimony.

To quickly review, such a category is needed for classification for eligibility, for tracking patients and clients, to develop critical data and needs assessments so that appropriate services and programs may be created, and to estimate the cost of funding needed for training and for the systems of service delivery.

At this time, RSA and NIHR are the only agencies that have created a head trauma category and made it a priority within their agencies.

We urge the formation of an interagency working committee that would report back to you again in a timely manner to, one, recommend a strategy in which the numerous agencies under HHS and the Department of Education can develop training, service access and linkages for communications.

Two, develop potential funding strategies to pool resources; for children, adolescents and adults who are traumatically head-injured. Currently needed services and therapies are not reimbursable for most victims.

We know there are 100,000 children in the United States severely head-injured.

To urge the implementation of a plan to establish a National Head Injury Registry. Urged by NHIF State Associations, a few States are establishing such registries by legislative mandate and support of rehabilitation commissions.

Four, to influence the development of systems of delivery of care and services ranging from acute medical management, rehabilitation, extended rehab, and community-based services in education, vocational training, independent living and respite care.

Cutbacks in these programs will not serve those currently eligible, never mind adding another population of those who also need these services.

As a parent representing other parents, family members and persons with head trauma, we are deeply frustrated by an Administration which makes broad statements encouraging rehabilitation, special education and other comprehensive services which lead to independence, productivity and dignity, then attempts to strip all health, human service and education programs to the bone.

The disabled population bears an undue portion of the deficit. We are convinced we will not succeed without strong, vital, energetic Federal and State support and participation in helping people with disabilities.

The private sector cannot bear the total burden for this population. We again depend on you.

Please know we will continue to do our part. We thank you for your past support and help for our future.

[The statement follows:]

**National
Head
Injury
Foundation,** Inc.

Gerald W. Bush, Ph.D., *President*
Marilyn Price Spivack, *Exec. Director, V.P.*
James Mikula, Ph.D.,
V.P. Professional Affairs
Judy Ferguson, *V.P. State Association Affairs*
Charles L. McLafferty, *Treasurer*
Tom Bowen, *Secretary*
Martin L. Spivack, M.D.,
Co-Founder, Past President

TESTIMONY OF
THE NATIONAL HEAD INJURY FOUNDATION
TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR HEALTH AND HUMAN SERVICES, EDUCATION
RELATIVE TO FISCAL YEAR 1987 APPROPRIATIONS FOR PROGRAMS AUTHORIZED BY THE REHABILITATION ACT OF 1973, AS AMENDED

SUBMITTED BY

GERALD BUSH, PH.D.
PRESIDENT

MARILYN PRICE SPIVACK
FOUNDER, EXECUTIVE DIRECTOR

MARTIN L. SPIVACK, M.D., PH.D
PAST PRESIDENT

APRIL 30, 1986

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The National Head Injury Foundation, Inc. (NHIF) is a growing organization of 30 State Associations, 315 chapters and 14,000 members providing support, information, education and advocacy for individuals suffering brain damage after head injuries. Once again, we want to emphasize that head injuries account for 500,000 hospital admissions each year and of these, 50,000 - 70,000 people are left with moderate to severe disability. Thousands more experience "minor" disabilities. The tragedy of traumatic brain injuries is multiplied by the fact that two-thirds occur to people under age 35. In fact, head injury is the most common cause of death and neurologic disability in the young. The report published by the Committee on Trauma Research, "Injury in America", refers to injuries as the "last major plague of our young".

This committee has been of enormous help to us, survivors, families and concerned professionals. Your legislative report language of 1984 led to the significant report of agencies under Health and Human Services (HHS) and the Department of Education of their activities relating to research training and service delivery surrounding the issues of Traumatic Brain Injury (TBI). The report was submitted and the NHIF added its' comments to that report. The result of that report was positive as it immediately led to an increasing interest and response to the NHIF communications with agencies under the Office of Special Education and Rehabilitative Services (OSERS), Interagency Committee on Handicapped Research, Social Security Disabilities Administration (SSDA), National Institute of Communicative Disorders and Stroke, National Institute of Mental Health, and Developmental Disabilities.

On May 14, 1985 NHIF entered into a cooperative agreement with OSERS. That Agreement has become a valuable working document that is already producing an increased awareness and interest in research, training and dissemination of information at the Federal and State levels. At this time, five NHIF State Associations have signed similar agreements and 23 states are working closely with their Department of Rehabilitation to implement head injury registries, needs assessments, training of counselors and special educators, and to study and plan for appropriate implementing and funding of a coordinated system of service delivery and case management. These same states are also working with members of the state legislatures for necessary authorizations and appropriations.

SPECIAL CATEGORIES. In 1984, Congress requested the report to address the need of establishing a specific category of disability for head injury and the utilization of that category by the relevant federal and state agencies. Over the past year, much discussion on this subject has taken place between the NHIF and several agencies including the Department of Education, Rehabilitation Services Administration (RSA), and the Social Security Administration. Other than RSA, to date no agency has listed TBI or Head Injury as a separate category of disability. Most importantly, the new SSDA listing of mental impairments does not single out head injury as a category. SSDA has added commentary to define appropriate methods of testing and evaluation. The NHIF is working with SSDA to disseminate education among social security evaluators, adjudicators, and physicians. NHIF will continue to urge the establishment of a specific category. We feel that a categorical listing is essential to encourage research, training and service delivery. Further, recognition by SSA and all pertinent agencies of "brain damage secondary to head injury" as a category will define the nature of the disability and track the needs of people with head injuries.

It is the purpose of the NHIF testimony this year to comment on some of the issues outlined above and to review the negative impact that the decreases in funding proposed by the Administration will have on people suffering disability from traumatic brain injury. We wish to add our voice to all those representing all disabled people asking that our country's disabled not be required to shoulder a disproportionate burden in the quest for deficit reduction.

REHABILITATION AFTER HEAD INJURY. The availability of "early" rehabilitation services after traumatic head injury has improved greatly over the past six years for a small percentage of survivors. The problem begins when the head injured person is discharged from the rehabilitation hospital to a community ill-prepared to provide the long-term services required for each individual to reach his or her full functional potential. The private sector has begun to develop such programs, but in general, they are expensive and available only to those with workman's compensation, private insurance coverages or to the beneficiaries of large insurance settlements. At the present time, there are no states with fully implemented systems of care providing appropriate programs and services leading to increased independence.

Although such a comprehensive system does not exist, there are hopeful signs that the situation is changing. Through the efforts of the NHIF and its' State Associations, and because of the expression of concern from both the House and Senate Subcommittees, there is an awareness of the problem which did not exist previously.

Some State Agencies with assistance from NHIF State Associations have taken it on themselves to seek funding at State levels, but it is abundantly clear that most states will be unable to implement new programs, and those just started will be in jeopardy if the budget for Vocational Rehabilitation State Grants is reduced to $1.1 billion for FY 87 as the Administration proposes. We join with the Consortium for Citizens with Developmental Disabilities (CCDD) and the National Rehabilitation Coalition (NRC) in requesting $1,379.2 million for this program.

SPECIAL DEMONSTRATION PROGRAMS. Since rehabilitation of head injured individuals is a relatively new field, Special Demonstration Programs under Section 311 of the Rehabilitation Act are essential to "expand and improve" rehabilitation services for this population. Under NHIF urging in 1984 and 1985, Head Injury was included as a specific priority category under this program. Five new projects may be funded at the average cost of $115,000 each. Under the President's budget request, these projects as well as others for other disabilities may not become a reality. Current projects would also be threatened. This committee is sympathetic with the critical importance of demonstrating new methodology and demonstration projects to improve vocational potential. We strongly endorse supported employment. It is the model of future hope for all severely impaired by traumatic head injuries. We strongly recommend the funding of $30.60 million for this program.

REHABILITATION TRAINING. In all rehabilitation, training of personnel is the most critical element in providing effective services to disabled people. Nowhere is this more true than in the rehabilitation of head injured people whose special programmatic needs are only beginning to be appreciated. By reducing the FY 87 congressional appropriation for rehabilitation training to $15 million, the Administration will make it impossible for RSA to institute any new initiative in this area. We urge the Committee to recommend funding of $32 million and, if achieved, request that RSA set aside specific funds for training of personnel in head injury rehabilitation.

EDUCATION OF HANDICAPPED CHILDREN. P.L. 94-142 (State and Local Grant Programs) is the backbone of special education programs for handicapped children. It is estimated that each year 110,000 children age 0-14 suffer head injuries caused by motor vehicle accidents, falls and child abuse. Clearly, most of these children will require special programs funded under P.L. 94-142. Reducing the funding level to $1,135.1 million will stop any progress in this area. We agree with CCDD that an appropriation of $1,435.6 million is necessary to allow Departments of Special Education to meet their responsibilities toward disabled children.

SPECIAL EDUCATION PERSONNEL DEVELOPMENT. As with rehabilitation programs, special education programs require trained personnel. This is particularly true when teaching a head injured child whose disabilities do not fit neatly into categories most educators are accustomed to. Because there are very few special education teachers knowledgeable about head injury, the NHIF has had a Special Education Task Force. The result of that effort has been published in a manual and a series of teaching conferences are planned. The first NHIF Special Education Conference was held in Massachusetts on December 5, 1985 for the N.E. Region Special Educators. We urge the Department of Education to set aside specific funds to train educators about head injured children. Clearly, that will not be possible if this budget is cut to $48 million as the Administration proposes. We strongly support an appropriation of $74 million.

DEVELOPMENTAL DISABILITIES. Since developmental disability includes individuals mentally handicapped prior to age 22, almost 50 percent of disabled head injured persons may fall into this category. The State developmental disability programs, if fully implemented, would provide the types of services required by head injured young people who "fall between the cracks" of other agencies. We recommend an appropriation of $56.5 million for FY 87 for the developmental disability basic state grants. Even at this level, the major burden will fall on the states for implementation.

INDEPENDENT LIVING SERVICES, Part A & Part B. Unfortunately, the programs have been specifically directed toward individuals with physical disability and thus most head injured people with cognitive and behavioral dysfunction have not been served. The NHIF urges RSA to encourage the development of I.L.C.'s for head injured people with or without physical disability as eligible for the Independent Living Services programs. To do this will require, at the very least, an appropriation of $26 million. We are also in full support of the CCDD in urging the appropriation of $30 million to continue the activation of Part A of Title VII of the Rehabilitation Act to provide for a comprehensive program of services for those individuals too severely handicapped to be eligible for current vocational rehabilitation services.

NATIONAL INSTITUTE OF HANDICAPPED RESEARCH (NIHR). If progress is to be made in rehabilitating individuals who are head injured back to productive lives, it is essential that new and innovative approaches in this area be developed. We are particularly interested in studies on cognitive retraining, use of computers, neuropsychological evaluation, psychosocial and behavioral remediation, pharmacologic therapies and innovative approaches to vocational retraining. Because of limited funding, the investigator/initiated research program was able to fund only a small percentage of applications. Funding at $39 million will seriously affect current projects when the need is to increase valuable rehabilitation research.

We recommend an appropriation level in FY 87 of $49 million. The NHIF expresses deep concern regarding the need to develop a system of coordinated care for victims of traumatic brain injury. We would ask this committee to allocate new moves to intensify research and propose the development of model systems of care.

Appropriations have not kept pace with neurological research opportunities. According to the 1985 CNS Trauma Report, the past decade has witnessed a new and improved understanding of the incidence and pathophysiology of secondary central nervous system insults for hypoxic, arterial hypertension and elevated intercranial pressure. This has allowed for altered therapeutic approaches and better outcome. We, according to Dr. Murry Goldstein, are on the threshhold of major advances in basic neuroscience. To cut back funding is to dramatically halt research that would negatively impact this important area for decades. According to the report "Injury in America", 4.1 million pre-retirement lives are lost each year to injury. 112 million Federal dollars were spent in FY 80. Head injuries are the major cause of such catastrophic disabilities. The NHIF fully supports the FY 1987 recommendation of CCDD of $505.0 million for the National Institute of Neurological and Communicative Disorders and Stroke.

NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH). We have talked to the NIMH director concerning the behavioral, emotional and psychosocial dysfunction suffered by many head injured individuals. The NHIF feels that research in the mechanisms causing these disabilities, as well as therapeutic techniques and pharmacologic intervention leading to remediation are within the purview of NIMH. We support the CCDD recommendation of $272.0 million for research, $27.6 million for research training, and $26 million for clinical training.

HEALTH CARE FINANCING ADMINISTRATION (HCFA). (Medicaid-Medicare.)
Currently, under the DRG systems patients with TBI are often discharged from the acute-care hospital prematurely without adequate rehabilitation. The patient oftentimes is transferred to a rehabilitation hospital. Utilization Review Boards restrict treatment under rigid time frames relating to patients' physical disability - medical requirements. Therefore, it has become essential for the HCFA to not only recognize TBI as a diagnostic category but also to establish funding levels for therapeutic techniques such as cognitive remediation, behavior modification and memory retraining as well as extended physical therapy, speech therapy and occupational therapy, psychological training.

REHABILITATION ACT OF 1973, AS AMENDED
($ in millions)

Program	FY86 Approp. priation	FY86 Post Sequestration	FY87 Authorization	Administration FY87 Budget	Coalition's Recommendation
Basic State Grant	$1,190.0	$1,145.0*	Pending	$1,100.0	$1,379.4
Evaluation (Sec. 14)	2.0	1.914	Pending	.6	2.0
Training	27.0	25.839	Pending	15.0	32.0
National Institute of Handicapped Research	44.0	42.108	Pending	39.0	49.0
Innovation & Expansion	9.0	8.613	Pending	9.0	9.0
Independent Living					
Comprehensive State Services, Part A	11.0	10.527	Pending	----	30.0
Centers for Indepen. Living, Part B	23.0	22.011	Pending	22.0	26.0
Services to Older Blind Individuals, Part C	5.0	4.785	Pending	----	5.5
Service Projects:					
Client Assistance	6.7	6.4119	Pending	6.3	7.5
Special Demonstration Projects	20.2	19.33	Pending	14.6	30.6
Projects with Industry	15.2	14.5464	Pending	13.0	18.0
Special Recreation Programs	2.2	2.1054	Pending	----	4.5
Helen Keller National Center	4.3	4.1151	Pending	4.2	5.5
Archit. and Trans. Barriers Compliance Board	1.97	1.89	Pending	1.97	2.5

*This represents the cost of living reduction for section 110.

Mr. NATCHER. Thank you very much, Mrs. Spivack. We want to thank all three of you for your appearance before the committee. You made an excellent statement.

Mr. Conte?

Mr. CONTE. I want to add my special welcome to Marilyn Spivack. She and her husband are an extremely effective pair. I have been happy and honored to work with them over the past few years, and I wish you well.

Ms. SPIVACK. Thank you and keep up your good work.

WEDNESDAY, APRIL 30, 1986.

REHABILITATION PROGRAMS

WITNESSES

MARTIN A. ADLER, DIRECTOR, HELEN KELLER NATIONAL CENTER
LILLIAN GARCIA, PARENT OF DEAF-BLIND CHILD

Mr. NATCHER. Our next witness is Mr. Martin Adler, and we will be pleased to hear from you.

Mr. ADLER. Mr. Chairman, members of the committee, again, thank you for inviting the Helen Keller National Center for Deaf-Blind Youths to testify before this committee. We have always had a deaf-blind consumer assist us in the testimony in requesting additional funds, and indicating the need for services.

We have already submitted our written testimony, so at this time, I would like to introduce a parent of a deaf-blind child, Mrs. Lillian Garcia from Florida.

Mr. NATCHER. We will be pleased to hear from you.

Ms. GARCIA. This is all new to me. I am very nervous. I am not a lobbyist. I am just a parent first. I know you are aware that parents are very unfamiliar with the complex government and local and State and Federal Government agencies, and which we frequently, because of our children being deaf and blind, have to access.

We as parents feel that we need training and support to acquire that knowledge and the skills, and particularly on how to deal and participate with the professionals.

I have a 17-year-old daughter who was born deaf and blind, and through the years, I have learned how to take care of her, how to work with other parents and encourage them to become involved.

I feel that parents are unique and with that unique knowledge that they have regarding their child, their perspective should be considered very vital and it should be maximized in benefiting the services for the deaf-blind children.

Many times, we parents have to deal with the physical, financial and emotional and social stress that goes along with raising a deaf-blind, a multi-handicapped child.

One particular emotion that we have to deal with from birth on up is rejection, not of just ourselves but of our children. We deal with the professionals, family and friends, as well in society and very often even the educational system.

As our child gets ready to get out of school, we have to deal with post-school rejection. There is no, or there are no available services. We had have to bury our dreams for a healthy child and learn to accept, live and love the child of reality.

We must live with the outcome of the educational process, which has a very profound impact on the aspects of the lives of each family member, and as well as that deaf-blind child, and this is a lifelong thing that we must deal with.

My husband passed away two years ago, at which time my daughter has since developed glaucoma, and with a bill $4,000 and a need to go back into the hospital, and we no longer have insurance on her, and therefore, she was rejected.

The financial strain that is created is tremendous. In addition, we find that in dealing with agencies, in trying to obtain services for our children, there is a lot of turfism.

We believe that there is a lot of negative attitudes that contribute to the lack of services, and we would like to see some of these attitudes changed.

We feel there are certain needs that need to be addressed immediately, and continuously, and we would like to see some increased available support services to the families.

We need to learn how to handle our deaf-blind child, learn how to access the system, and able to endure the frustration of the uncoordinated, unsympathetic service providers and the society's attitude.

We feel that we need ongoing training and support to learn how to be an advocate, and we appreciate Helen Keller for helping us to do that. They are helping train us to do that.

The educational programs are totally not preparing the children to become a part of society. They are lacking the appropriate life skills and we feel that more emphasis needs to be made on a smooth move from the school system into community services.

We would hope that possibly there would be some help from a mandate that a lead agency or one agency in each State would be held accountable for providing and connecting those services.

Often, decisions are made on an assumption by people who do not live an everyday life with these children, and we would like to hope that the parents would be considered a part of decisionmaking for the services for these children.

Being deaf-blind, being multi-handicapped creates a very isolatory situation with these people. They lack the ability to communicate, and it is very devastating to them.

We feel that there needs to be some changes in attitude in the sensitivity for the human needs of people. We would like for our kids to have a quality of life, and not just an existence.

Being born, or dealing with the deaf-blind child from birth creates a tremendous emotional impact on the whole family unit. Often, it creates divorce and many of these children are raised by single parents.

They are unable to care for these children constantly, and there is no available resource in many instances to receive relief or respite care. They need to get away and gain their strength and direction.

We hope to see some funding shifts, possibly increases, to support community services. We don't want to see our children revert back to warehousing institutions. 94-142 has created a law that has given us some strength and security, and we ask that possibly that be considered for the children after school, that some type of a law be mandated to secure services ongoing lifelong for our children.

We feel specialized residential and day work programs need to be established immediately. The deaf-blind have unique needs. They need training and education lifelong, because of their isolation from the world, and also they are locked within themselves, because of their deaf-blindness, and because of this, they primarily will need some defense at various degrees all of their life.

Rehabilitation agencies, I feel, are not serving our deaf-blind children. The multi-handicapped need approaches from many agencies, and not just retardation agencies.

We know that our children, because of their needs and dependency, and their poor ability to communicate, that they will not be able to be totally independent, and they will need support in their employment and daily living.

We parents would like to ask for some assurance that services could be available to our children after they leave the school system. We ask for you to help us. We need a system review possibly to increase incentives to the community, so that services would be opened up to the deaf-blind and multi-handicapped.

Parents are being penalized if they wish to keep their children at home after a school system is finished with them. They will allow them to live in their home, but day programs and services are not available to them unless they relinquish the child or abandon them to the system.

Something is wrong. If we wish to help out, we feel possibly some equal services could be available to those that wished to keep their child at home.

We would like some review of the health insurance that is available to multi-handicapped disabled people and make it available to them, and not wait until the family has to go on total welfare, and the burden on the whole family beyond the system, not just the health costs.

Thank you very much.

Mr. NATCHER. Mrs. Garcia, thank you for your statement. We appreciate you coming. You made an excellent statement. You can rest assured that all of the members of this subcommittee are certainly going to give every consideration to your request, and Mr. Adler, it is a pleasure to have you appear again before our committee.

[The statement of Mr. Adler and Ms. Garcia follows:]

STATEMENT

TO

SUBCOMMITTEE ON

LABOR, HEALTH AND HUMAN SERVICES

AND

EDUCATION AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

RE

HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

OPERATED BY

HELEN KELLER SERVICES FOR THE BLIND

WITNESSES APPEARING:

MARTIN A. ADLER, MSW, ACSW
DIRECTOR
HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS
111 MIDDLE NECK ROAD
SANDS POINT, NEW YORK 11050

AND

LILLIAN GARCIA
PARENT OF DEAF-BLIND CHILD
AND
PRESIDENT
FLORIDA ASSOCIATION FOR THE DEAF-BLIND & MULTIPLY HANDICAPPED
1741 JEFFERSON ROAD
JACKSONVILLE, FLORIDA 32216

2:15 PM
APRIL 30, 1986

Mr. Chairman and Honorable Members of the Subcommittee:

Thank you for inviting us to testify before the Subcommittee in regard to our request for the reauthorization of the Helen Keller National Center for Deaf-Blind Youths and Adults. My name is Martin A. Adler and I am the Director of HKNC. I am also accompanied by Mrs. Lillian Garcia, President of the Florida Association for the Deaf-Blind and a parent of a deaf-blind child.

HKNC is operated by the Board of Trustees of what was formerly The Industrial Home for the Blind (IHB) and is now the Helen Keller Services for the Blind under an agreement signed in 1969 with the United States Department of Health, Education and Welfare. The authorization for our operation is now contained within Title II of the Rehabilitation Amendments of 1984. We operate under the general supervision of the Rehabilitation Services Administration. The Center's headquarters is located on a 25-acre wooded site in Sands Point, New York. The training, research and Administration building, as well as the residence building, are specially designed and equipped to meet the accessibility and safety needs of clients served.

Though the Helen Keller National Center has been in operation since 1969, it became operational in its new Sands Point, N.Y. facility in 1976. For several years there was the process of managing the growth, development, provision of services to the deaf-blind, training of staff and developing a conceptual and operational framework of delivering services to deaf-blind persons, their families and agencies. A complete framework of a service delivery system had to be developed without precedent and/or based upon previous operating models. Now, a full national system is in place and has been providing comprehensive services to the estimated 40,000 target population, their families, and agencies. HKNC has developed a field service system that has provided over $1.2 million to agencies, both public and private, enabling them to develop local service delivery programs for the deaf-blind. Training for hundreds of professionals in the field and at headquarters in modalities applicable to the deaf-blind has been accomplished as well as providing direct services to hundreds of deaf-blind individuals and their families through our ten regional offices.

The HKNC evaluation and rehabilitation program at the headquarters site continues to meet and fulfill the original congressional mandate. We have demonstrated that most deaf-blind persons can participate in the rehabilitative process and achieve notable improvement. About 43% of clients who received training at headquarters are currently in some form of remunerative employment. Most others have achieved a level of adjustment that enables them to reside outside of institutional care. Families have a greater feeling of hope that their deaf-blind son or daughter can now communicate more effectively, relate and care for many of their own basic needs. Our field services have stimulated many states (about 17) to develop programs and coordinating staff to work with the deaf-blind. Our National Training Team and Technical Assistance Team have provided training opportunities for hundreds of professionals. The HKNC Affiliation Network System has provided funds and direction for some 26 state and private agencies to start or expand programs for the deaf-blind. Our outreach services in the field and expanded services at headquarters have resulted in an explosion of interest throughout the country, both on a public and a private level, to develop services for deaf-blind individuals. Thus, our purpose and one of our original mandates had been achieved, i.e. to demonstrate that rehabilitation can be successful with deaf-blind individuals.

The methodologies developed within the HKNC Service Delivery System have positively impacted on the rehabilitative approaches and techniques of some other severely handicapped adult groups. Perhaps the most significant carry-over has been to stimulate agency administrators and staff to expect more positive results in their work with other severely handicapped individuals. It is not infrequent for staff participating in seminars or receiving technical assistance to transfer a helpful method in working with deaf-blind to their target population. Our Technical Assistance Team has documented this carry-over relationship in almost all of their workshops. For example, the areas of carry-over have been related to our techniques in developing community based housing, funding, training of staff and community response. Another area has been the modalities utilized in preparing handicapped individuals for community living through Independent Living Centers. Our systems have supported and improved those institutional systems working with the severely mentally retarded and other developmentally disabled groups.

The recreation and leisure time craft techniques developed at HKNC have been implemented in numerous institutions where their population functions on levels similar to many of our clients. Home economics for the deaf-blind has been implemented in other systems as well as training parents in "how to" methods of teaching their severely handicapped homebound children some additional cooking and self-care skills. As a result, some attitudinal changes have contributed to further deinstitutionalization programs, technical assistance, and appointing state coordinators for the deaf-blind.

We are now entering another stage of development within HKNC. As a result of a recent needs assessment response from 196 agencies, a total of 793 needs were identified, or an average of four per respondent. Analysis of the needs assessment data reflects the following priorities:

1. Technical assistance in Independent Living, including training, development of group homes, and community-based housing alternatives, was requested by 117 of the 196 agencies (60%)
2. Technical assistance in vocational services was requested by 110 of the 196 agencies (56%)
3. Technical assistance in rehabilitation models/methods/techniques was requested by 60 of the 196 agencies (37%)

In reviewing these priorities, HKNC wishes to expand the following areas:

At the present time, we have 10 regional offices staffed by ten regional representatives and part-time secretaries. They are frequently requested to provide technical assistance, client contact, agency consultation and other forms of work activity related to serving deaf-blind persons. Using an analogy of the private business environment, the marketplace is asking for more services and we are unable to meet the full demand. The present level of salary funding for all regional personnel is approximately $427,000 per annum. There is a need to double the number of regional representatives available for service in the field. This would increase that category to approximately $850,000.

There is a need to expand our vocational services at headquarters, particularly in relation to the increased numbers of low functioning multihandicapped rubella clients entering the rehabilitation system at Sands Point. Specific staff needed: Two additional behavior modification specialists, a prevocational specialist, and two more daily living skills instructors. This increase would cost approximately $147,000 per annum.

The need for training personnel in the field has also increased. Our three staffed National Training Team should be doubled to a cost of approximately $120,000 per annum.

Three other areas are also crucial to the service delivery system for deaf-blind persons. We are developing a Quality Assurance/Evaluation program that should be finalized, tested and then exported to the field. This would aid in research and in developing further cost-effective and efficient systems. Approximately $50,000 per annum is needed. A research and training center related to the deaf-blind is crucial. The cost for this would be approximately $100,000.

The final third area has to do with the maintenance and capital improvement of our physical facility in Sands Point, which is approaching its tenth year of operation. Approximately $8. million had been expended in 1976 for the construction of this facility. Many of the earlier construction and design problems are now making themselves felt in the maintenance of the building and the mechanical equipment. A preventive maintenance program must be instituted and this would cost approximately $75,000.

Meeting the critical needs described above would require an increase of approximately $1.3 million in appropriations for the Center in FY-87. In recognition of fiscal realities, however, and balancing those against the very real and immediate financial needs of the deaf-blind and the needs of the Center in meeting the demand for increased services, which include training and research, the Helen Keller National Center urges reauthorization of its appropriations at the following levels: $5.0 million for FY-87; $5.5 million for FY-88; and $6.2 million for FY-89. In the event such levels cannot be authorized, however, the Center's authorizations should be reflected as "such sums as may be appropriated" for the next three fiscal years.

We at HKNC feel we have accomplished what was necessary to demonstrate the benefits of a National Service Delivery System for the Deaf-Blind and we are ready for turther programs to fulfill the needs of the deaf-blind population.

WEDNESDAY, APRIL 30, 1986.

REHABILITATION PROGRAMS

WITNESS

VINCENT GRAY, EXECUTIVE DIRECTOR FOR D.C., ASSOCIATION FOR RETARDED CITIZENS OF THE U.S.

Mr. NATCHER. Our next witness is Mr. Vincent Gray. Mr. Gray, we will be pleased to hear from you at this time.

Mr. GRAY. Mr. Chairman, Mr. Conte, Mr. Porter, good afternoon. I am Vincent C. Gray, Executive Director of the Association for Retarded Citizens here in Washington, D.C., and I am pleased to represent the Association for Retarded Citizens of the United States today in presenting our testimony.

Let me begin by saying on behalf of the Association for Retarded Citizens, I want to thank you for this opportunity to testify on the subject of Federal funding for programs affecting persons with mental retardation, and their families.

The ARC funding recommendations that follow are testimony to the progress that we, as a Nation, have made in the last 25 years toward improving the lives of persons with mental retardation.

The recommendations that we are submitting to you today are admittedly modest, because we recognize that the current economic and political climate will only attend to moderate adjustments of the status quo.

That should not be misinterpreted by Congress to mean that our recommendations represent appropriations levels that will, if enacted, completely meet the needs of persons with mental retardation. Indeed, they will not.

The needs of persons with mental retardation and their families significantly exceed the current level of Federal assistance available to them. Today, thousands of persons with mental retardation and their families are waiting, waiting for their government to expand services so that they may receive them.

We are talking about young babies and infants, born retarded, whose handicapping condition can be significantly ameliorated with infant stimulation and early childhood programs, yet access to such programs is rare, due to lack of program availability.

This is extremely short-sighted since such programs have proven to enhance the child's ability to become more independent and self-sufficient later in life, thus saving countless government dollars by avoiding costly and unwarranted institutionalization, lifelong income maintenance payments and other Federal programs and benefits.

The same is true for other vital services funded in whole or in part by the Federal Government that simply are not available to many eligible individuals with mental retardation.

For example, many have excellent potential for employment as adults but can't access vocational rehabilitation services, due to a shortage of funds by rehabilitation agencies.

Their inability to obtain job training and thus not enter the world of work, not only shatters the self-respect of persons with retardation, but is a terrible waste to society.

These potential taxpayers are relegated to be tax burdens, not because there are no jobs or that these persons are unable or unwilling to work, but because our society has not prioritized utilizing these persons' potential and worth. Such occurrences are happening daily throughout our country and are quite sad and frustrating.

Thousands of persons with mental retardation languish in large, costly institutions because there is not enough money to develop less costly but much better programs to meet their individual needs in the community.

Many adults with mental retardation still live at home with their aging parents since there are no community services to care for them.

These aging parents live in constant fear of the day they will be unable to care for their dependent child. Their only option, without community-based services available, is institutionalization. That is an option that is dreaded, I assure you.

Mr. Chairman, these three little scenarios are very disconcerting to our members, since it is their sons and daughters, brothers and sisters and friends who are on the short end of our Nation's economic policies.

Our members are clearly aware of the huge burdens facing this Congress and this subcommittee as you attempt to implement the Gramm-Rudman-Hollings Federal Deficit Reduction Act.

We are taxpayers and we strongly support a sound economic policy leading to sizable reduction in the deficit. We are equally strongly supportive that our Nation's children and adults with mental retardation and other disabilities not be asked to shoulder a disproportionate burden to achieve this goal.

Most of the Federal programs which serve this population are serving fewer people today than they did in 1979. This is not progress. We now anticipate even further reductions. What are these families to do?

Mr. Chairman, members of the subcommittee, the ARC appreciates your fine efforts in the past on behalf of persons with mental retardation. The funding recommendations which follow are a minimum of what is needed to simply maintain current service levels.

Anything less than these figures will mean a cut in services to mentally retarded persons and their families. Any form of a freeze of appropriations will mean fewer services and longer waiting lists.

We believe it is simply unfair to fund these critical programs at anything less than last year's service level. At a minimum, fiscal year 1986 pre-sequestration levels must be maintained in the fiscal year 1987 appropriations, with an adjustment for inflation.

The attached chart lists the several programs which provide the bulk of services, benefits, prevention and research initiatives to assist persons with mental retardation. We urge the Congress to appropriate for these programs the sums contained in the right-hand column.

The ARC most strongly supports those programs which contribute significantly to the lives of persons with mental retardation and other disabilities.

Although all of the programs contained in the chart are important, the Association for Retarded Citizens has prioritized the following programs continued within the Departments of Health and Human Services, Labor and Education.

Allow me to briefly mention those numbers to you very quickly.

As far as the Education for Handicapped Children State Grant is concerned, we recommend an appropriation of $1,360,000,000, which will enable school systems to receive 12 percent of the excess cost of educating a child with handicaps, thus returning us to the 1979 reimbursement rate.

With regard to the Vocational Rehabilitation State Grant, we recommend an appropriation of $1,379,000,000, which will assist people who are retarded or have other disabilities, and have employment potential to be trained for jobs.

Title XX Social Services Block Grant: The ARC recommends an appropriation of $3,300,000,000 to provide community-based services such as group home living, extended sheltered employment, and respite services.

Developmental Disabilities State Grant: The ARC recommends an appropriation of $56,500,000 to fund the new employment service priority mandated by the Developmental Disabilities Act to be implemented in fiscal year 1987.

Independent Living State Grant (Part A): The ARC recommends $30,000,000 to fund statewide services to individuals with mental retardation and other disabilities whose disabilities are so severe as to preclude their eligibility for vocational rehabilitation services.

Maternal and Child Health Block Grant: The ARC recommends an appropriation of $600,000,000 to provide services to chronically ill and disabled children and their families and to needy and impoverished mothers.

Thank you for this opportunity, and we certainly look forward to your support.

Mr. NATCHER. Thank you, Mr. Gray. We appreciate your appearance.

[The information follows:]

Summary Table

	FY 1985 Appropria-tion	FY 1986 Enacted	FY 1986 Post Se-quester	FY 1987 Authori-zation	President's 1987 Re-quest	ARC Recom-mendation
DEVELOPMENTAL DISABILITIES PROGRAMS						
DD Basic State Grants	50.25	53.4	51.1	56.5	50.25	56.5
DD Protection & Advocacy Systems	13.75	14.6	13.97	15.5	13.75	15.5
DD University Affiliated Facilities	9.0	9.6	9.1	10.1	9.0	10.1
DD Special Projects	2.7	2.8	2.7	3.1	0	3.1
EDUCATION OF HANDICAPPED CHILDREN						
State and Local Grant Program (PL 94-142)	1,135.1	1,215.55	1,163.28	formula	1,135.1	1,435.6
Preschool Incentive Grants	29.0	30.0	28.71	79.8	31.0	47.9
Early Childhood Education	22.5	24.0	22.96	pending	22.5	28.3
Secondard Education and Transitional Service	6.33	6.6	6.32	pending	6.33	7.00
Postsecondary Education Programs	5.3	5.5	5.264	pending	5.3	6.00
Special Education Personnel Development	61.0	64.0	61.25	pending	48.0	74.0
State-Operated Programs (PL 89-313)	150.2	150.2	143.7	formula	150.2	167.0
Vocational Education	666.5	782.4	748.7	such sums	387.2	782.4
REHABILITATION RELATED SERVICES						
Vocational Rehabilitation State Grants	1,100.0	1,190.0	1,145.15	pending	1,100.0	1,379.2
Rehabilitation Training	22.0	27.0	25.84	pending	15.0	32.0
Comprehensive State Services for Independent Living - Part A	5.0	11.0	10.537	pending	0	30.0
Centers for Independent Living - Part B	22.0	23.0	22.01	pending	22.0	26.0
Independent Living Services for Older Blind Individuals - Part C	0	5.00	4.73	pending	0	5.50
Protection and Advocacy - Part D	0	0	0	pending	0	6.0
Special Demonstration Programs	14.64	20.20	19.33	pending	14.64	30.60*
Projects with Industry	14.4	15.2	14.5	pending	13.0	18.0
Special Recreation Programs	2.1	2.2	2.1	pending	0	4.5
Client Assistance Program	6.3	6.7	6.412	pending	6.3	7.5
National Institute of Handicapped Research	39.0	44.0	42.11	pending	39.0	49.0
Innovation and Expansion Grants	0	9.0	8.61	pending	9.0	9.0
BLOCK GRANT PROGRAMS						
Title XX Social Services Block Grant	2,725.0	2,700.0	2,583.9	2,700.0	2,700.0	3,300.0
Maternal and Child Health Block Grant	478.0	478.0	457.4	478.0	478.0	600.0
MCH Special Projects (SPRANS)	71.7	71.7	68.6	71.7	71.7	90.0
Child Abuse	200.0	207.0	198.10	266.0	200.0	266.0
Alcohol, Drug Abuse and Mental Health Block Grant	490.0	490.0	468.9	576.0	490.0	576.0
Alcohol, Drug Abuse and Mental Health State Planning	2.5	0	0	such sums	0	5.0
PREVENTION PROGRAMS						
Women's Infants' & Children's Supplementary Feeding Program	1,500.0	1,560.6	1,560.6	pending	1,617.0	1,632.0
Immuniziation Program State Grants	42.4	47.4	45.3	65.0	47.7	65.0

*Includes transfer of $9 million from Section 121

(cont'd)

SUMMARY TABLE

BIOMEDICAL AND BEHAVIORAL RESEARCH	FY 1985 Appropria-tion	FY 1986 Enacted	FY 1986 Post Se-quester	FY 1987 Authori-zation	President's 1987 Re-quest	ARC Recom-mendation
National Institute of Child Health & Human Development	313.3	322.3	295.8	such sums	309.1	377.0
National Institute of Neurological & Communicative Disorders & Stroke	396.89	433.36	414.73	such sums	399.35	505.0
National Institute of Mental Health Research	196.2	214.0	204.8	such sums	199.9	272.0
National Institute of Mental Health Research Training	18.0	18.0	17.2	such sums	15.8	27.6
National Institute of Mental Health Clinical Training	22.0	22.0	19.1	such sums	0	26.0
National Institute of Allergy & Infectious Diseases	344.34	356.72	341.39	such sums	330.55	459.98
SPECIAL CONCERNS						
Architectural & Transportation Barriers Compliance Board	2.0	1.97	1.89	pending	1.97	2.5
Child Welfare Services (Title IV-B)	200.0	207.0	198.10	266.0	200.0	266.0
Foster Grandparents Programs	56.1	56.1	53.7	58.7	56.1	58.7
Job Training Partnership Act - Block Grants	1,886.15	1,863.20	1,783.10	such sums	1,820.00	1,969.40
Job Training Partnership Act - Pilots and Demonstrations	20.7	20.7	19.8	such sums	40.7	40.7
Legal Services Corporation	313.0	305.5	292.4	pending	0	387.0
Mental Health Services Demonstrations	10.5	12.5	11.9	20.0	0.0	20.0
National Council on the Handicapped	.750	.765	.732	such sums	.850	.850
Project Head Start	1.075	1.087	1.040	pending	1.075	1.221
Small Business Administration Handicapped Assistance Direct Loans	20.0	20.0	19.2	pending	0	20.0
Mental Health Protection & Advocacy System	0	10.0	9.57	pending	0	11.0
HOUSING PROGRAMS						
Section 202 Direct Loan Program	597.0	631.0	603.9	pending	30.3	656.9
Section 8 Housing Assistance Payments	7,173.5	9,815.6	9,393.5	pending	2,000.6	10,218.0
Congregate Housing Services	4.10	2.67	2.56	pending	0	4.27
Community Development Block Grant	3,472.0	3,124.0	2,990.4	pending	2,124.8	3,252.1
Farmers Home Administration (Section 515)	903.3	700.0	669.9		0	728.7
FmHA Rental Assistance	116.0	167.5	160.3		0	174.4
FmHA Community Facility Loans	115.9	100.0	95.7		0	104.1

ENTITLEMENT PROGRAMS	FY 85 Actual	FY 86 Estimated	FY 87 Proposed Budget	
			Current Law	Proposed Outlays
Social Security Disability Insurance	19,372.3	20,426.1	21,088.4	21,088.4
Supplemental Security Income	9,606.4	10,161.8	10,569.3	10,535.0
Medicare - Client Benefits	69,518.0	72,716.0	79,587.0	77,528.0
Medicare - Total	71,398.0	74,572.0	81,543.0	79,479.0
Medicaid - Client Benefits	21,393.0	23,401.0	24,750.0	23,620.0
Medicaid - Total	22.664	24.686	26.098	24.708
Food Stamps	11,701.0	11,733.0*	11,820.0	11,504.0
Foster Care	517.1	507.6	583.3	544.3
Adoption Assistance	35.4	41.9	59.9	59.9

*includes sequestration of administrative cost

WEDNESDAY, APRIL 30, 1986.

APPROPRIATIONS IMPACTING ON PERSONS WITH DEVELOPMENTAL DISABILITIES

WITNESSES

JAMES STEARNS, VICE CHAIRPERSON, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

ALLAN I. BERGMAN, DEPUTY DIRECTOR, UCPA GOVERNMENTAL ACTIVITIES OFFICE

Mr. NATCHER. Our next witness is Mr. Stearns. Come around, Mr. Stearns.

Mr. STEARNS. Thank you, Mr. Chairman.

My name is James Stearns, and on my left is Allan Bergman, Deputy Director of United Cerebral Palsy's Washington Office. I am an associate with the law firm of Barnett and Alagia in Washington, D.C. I am testifying today in my volunteer capacity as Vice Chairperson of the Governmental Activities Committee of United Cerebral Palsy Associations, Inc.

UCPA is a private nonprofit agency, with over 220 affiliates in 45 States, concerned with meeting the needs of persons with cerebral palsy and similar disabilities. I will summarize my statement and leave you with some of the views of how I as an individual with cerebral palsy became a Washington lawyer, which sometimes in the halls of Congress is a double-edged sword.

In New Hampshire, many years ago, I saw how these programs helped me to come here to Washington.

Mr. Chairman, for example, if we look at the program, the education of the handicapped children, State and local grant program, as you know, under that program, the Federal Government maintains a partnership with State and local education agencies to provide a free, appropriate special education and related services for children with handicaps.

I came through the system before that was law.

The benefits of the Federal mandate have brought new hope to thousands of parents with children who have cerebral palsy. However, while much progress has been made in the implementation of Public Law 94-142, we are distressed that the Congress has not lived up to the fiscal promise it made when it enacted the law.

Originally, the law authorized the Federal Government to pay for up to 40 percent of the national average per-pupil expenditure.

The Administration proposes to totally eliminate the $80,000,000 increase Congress appropriated in fiscal year 1986 and reduce the per-pupil expenditure to a new low of 7 percent. Mr. Chairman, we can't do that.

You have a narrow window of opportunity here. People like Jim Stearns need the help at the younger ages or they do not get the services at the appropriate time, so we are joining with a consortium of citizens in recommending that the State Grant Program authorized by Public Law 94-142 receive $1,435,000,000 in fiscal year 1987.

That is just increasing the percentages to approximately 12 percent, which is the program's funding level during the 1970s, and we ask consideration for that.

The second program is the Early Childhood Program. Mr. Chairman, cerebral palsy, such as I have, occurs prior to, during or shortly after birth.

In essence, in the 1970s, with a grant from the Department of Education, UCPA assisted over 100 community agencies in 30 States to establish a program for young children with cerebral palsy and other severe disabilities.

We have not kept pace with what we need to do in the area. Therefore, UCPA recommends this pre-school incentive grant program receive $47,900,000, and the Early Childhood Education Program receive $2,300,000 at the fiscal year 1986 authorization level.

We got to keep those numbers up to continue the good work of that program.

The third area we want to talk about briefly is parent training. Three years ago, Congress amended the Special Education Personnel Development Program, to set aside 10 percent of the funding for parent training.

As you probably already know, the stress and strain on parents who all of a sudden have handicapped children is astronomical, and I can speak from personal experience.

The Administration has recommended a 25-percent reduction in funding for this program. Such a reduction in funding would undermine the growing effectiveness of the parent training program.

UCPA joins with the Consortium on DD and recommends the Special Education Development Program receive 74,000,000 in fiscal year 1987.

My prepared statement talks about increases for the Vocational Rehabilitation Basic State Grant Program, funding for Independent Living, and talks about another critical area, which is getting the disabied into the Job Training Partnership Act.

I ask you, because I know time is short, to consider the record on these points.

We have people who enter this society with cerebral palsy. We start in good faith to legislate and give them the programs they need to become productive citizens.

We mean to do good when we put that legislation together. During different funding cycles, money stops and the program stops. What you are doing here is vital, and I close my testimony rather with a statement I began it with.

In some ways, in talking to you gentlemen who were here doing this job before I came to Washington, really the people that gave people like myself a chance, I know I am not telling you anything that you probably don't know, but I am urging you to keep up that fight, not only for myself, and the people I represent, or try to represent, but also for those people who just don't have a voice.

You have done superb work, keep it up please, look at the numbers and consider that which I have not gotten to in my testimony.

Mr. **Natcher**. Thank you very much, Mr. Stearns, you have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Stearns follows:]

STATEMENT

RESPECTFULLY SUBMITTED

TO THE

LABOR, HEALTH AND HUMAN SERVICES

AND EDUCATION APPROPRIATIONS SUBCOMMITTEE

OF THE HOUSE COMMITTEE ON APPROPRIATIONS

ON

F.Y. 1987 APPROPRIATIONS IMPACTING ON

PERSONS WITH DEVELOPMENTAL DISABILITIES

ON BEHALF OF

United Cerebral Palsy Associations, Inc.

1522 K Street, N.W.
Suite 1112
Washington, D.C. 20005

Witness: Mr. Jim Stearns
Vice-Chairperson
UCPA Governmental
Activities Committee
Washington, D.C.

Accompanied by: Allan I. Bergman, Deputy Director
UCPA Governmental Activities Office

April 30, 1986

INTRODUCTION

My name is Jim Stearns. I am an associate with the law firm of Barnett and Alagia in Washington, D.C. I am testifying today in my volunteer capacity as vice-chairperson of the Governmental Activities Committee of United Cerebral Palsy Associations, Inc. UCPA is a private nonprofit agency, with over 220 affiliates in 45 states, concerned with meeting the needs of persons with cerebral palsy and similar disabilities. Each year on a local, state and national level, over one million volunteers and professionals work together to improve the lives of children and adults with cerebral palsy and their families.

Despite the substantial commitment of volunteer time and the contribution of millions of dollars by the private sector to UCP affiliates last year, there is as critical a need as ever before for a strong federal presence in the lives of people with severe disabilities. During the past five years, despite vital support from Congress, we have seen a steady erosion of federal programs and benefits afforded to citizens with severe disabilities. Even the strong private sector support cannot keep pace with declining federal dollars.

As this Subcommittee makes important choices in the weeks ahead, it is important that it be understood that despite federal mandates enacted by Congress, children and adults with cerebral palsy remain on long waiting lists for educational programs and community services that would enable them to become more independent and productive.

Although there are some 20 programs within your jurisdiction that are important to UCPA and the people we serve, we would like to focus our testimony on several programs under the Education of the Handicapped Act (EHA), the Rehabilitation Act, the Job Training Partnership Act (JTPA), and the Developmental Disabilities Act.

EDUCATION OF HANDICAPPED CHILDREN (P.L. 94-142)

STATE AND LOCAL GRANT PROGRAM

Under EHA, the federal government maintains a partership with state and local education agencies to provide a free, appropriate special education and related services for children with handicaps. The benefits of the federal mandate have brought new hope to thousands of parents with children who have cerebral palsy. However, while much progress has been made in the implementation of P.L. 94-142, we are distressed that the Congress has not lived up to the fiscal promise it made when it enacted the law. Originally, the law authorized the federal government to pay for up to 40% of the National Average Per Pupil Expenditure (NAPPE). The Administration proposes to totally eliminate the $80 million increase Congress appropriated in F.Y. 1986 and reduce the per pupil expenditure to a new low of 7%.

Handicapped children and their parents are clearly suffering from the continuing failure of the federal government to provide a fiscal contribution at a more reasonable percentage. The adverse impact on handicapped children include children from coast to coast waiting for speech and physical therapy, class sizes growing larger and, in spite of the federal mandate, children with severe disabilities being told to stay at home because of the lack of available programs.

Approval of the Administration's funding recommendation would make a bad situation even worse. UCPA joins with the Consortium for Citizens with Developmental Disabilities in recommending that the State Grant Program authorized by P.L. 94-142, receive $1.435 billion in F.Y. 1987. This would increase the NAPPE to approximately 12%, which was the program's funding level during the 1970's.

EARLY CHILDHOOD PROGRAMS

UCPA is also concerned about preschool services for young children with handicaps. Cerebral palsy usually occurs prior to, during, or shortly after birth. In the 1970's, with a grant from the Department of Education, UCPA assisted over 100 community agencies in 30 states establish early intervention programs for young children with cerebral palsy and other severe disabilities.

Numerous studies have documented the benefits of early intervention as a program that reduces the need for later, more costly services. The most recent Annual Report of the Department of Education on the implementation of the Education of the Handicapped Act refers to a study showing that the return on the initial investment for children with disabilities who receive two years of preschool education was three-and-one-half times the cost for these services in reduced future education costs compared to children who did not receive preschool education. Despite these findings, three out of four children with handicaps in the preschool age range are not receiving these services.

There are two programs that focus on the unique special education needs of young disabled children. UCPA recommends that the Preschool Incentive Grant Program receive $47.9 million, and the Early Childhood Education Program receive $28.3 million as its F.Y. 1986 authorization level. These appropriation levels for F.Y. 1987 would allow the states and community-based agencies like UCP to reach out to a significant number of the unserved population for which early intervention services are critically needed.

PARENT TRAINING

Three years ago, Congress amended the Special Education Personnel Development Program to set aside 10% of the funding for parent training. These information and training programs enable parents to participate more effectively with professionals in meeting the educational needs of their children who have disabilities. These programs are of critical importance to new parents who have recently learned their child has a disability, as well as to thousands of parents who want to become actively involved and more informed decision-makers in the provision of appropriate special education and related services for their children. Parent information and training programs have improved the quality of education in 34 states. Unfortunately, 16 states still do not have a federally funded training program for parents.

The Administration has recommended a 25% reduction in funding for this program. Such a reduction in funding would drastically undermine the growing effectiveness of the parent training programs as well as continue critical shortages in a majority of states of qualified special education and related services professionals.

UCPA joins with CCDD in recommending that the Special Education Personnel Development Program receive $74 million in F.Y. 1987.

VOCATIONAL REHABILITATION BASIC STATE GRANT PROGRAM

Section 110 of the Rehabilitation Act authorizes the federal government to enter into partnership with states to provide rehabilitation services to persons with disabilities. As for most Americans, a major prerequisite to economic self-sufficiency for individuals with disabilities is a job. However, studies indicate that only one-third of youths with disabilities leaving school graduate to a job or some form of higher education. Of the approximately 12.9 million working-age persons reporting a work disability, only 4.2 million (or 32%) were working at the time of the 1980 census.

The State Grant Program is a most important source of funds for individuals with cerebral palsy and other disabilities. The goal of services offered by vocational rehabilitation agencies is to enable the disabled person to become gainfully employed. The President's request that funding for Section 110 be reduced to the F.Y. 1985 funding level would result in a continued weakening of the purchasing power of the rehabilitation dollar and a continued decline in the number of persons served and rehabilitated into employment. It is estimated that 85,000 fewer individuals would be served if the Congress accepts the Administration's funding level.

Since persons with disabilities represent the largest class of unemployed citizens in this country, UCPA is shocked and dismayed by such a recommendation. UCPA joins with CCDD and the Council of State Administrators of Vocational Rehabilitation in recommending an F.Y. 1987 funding level of $1.379 billion. The benefits of this appropriation will result in greater independence, productivity, social status, financial security and tax-paying status for thousands of disabled individuals.

INDEPENDENT LIVING

The "Rehabilitation Amendments of 1984" reauthorized Title VII of the Act which establisahed comprehensive services for independent living. The target population was those persons whose disabilities may be so severe that we have not yet developed the technology to tap their potential for employment, but who may benefit from services that may enable them to live and function more independently.

When Congress originally enacted State Services for Independent Living (Part A) in 1978, a funding level of $200 million was authorized. This amount was viewed as the minimum necessary to address the needs of individuals who have severe disabilities. In F.Y. 1986, Congress appropriated $11 million to "establish a sound basis for future additional funding." UCPA joins with CCDD in recommending that Part A of Title VII receive $30 million to begin to serve more adequately persons with the most severe disabilities.

UCPA is equally supportive of the Independent Living Centers funded under Part B of Title VII. These centers are presently serving more than 30,000 individuals with severe disabilities. Independent Living Centers are cost-effective alternatives to institutional care for people with disabilities. UCPA urges you to reject the President's request to return the program to its F.Y. 1985 funding level and approve an appropriation of $26 million which will allow for a modest growth in the number of Centers nationwide.

NATIONAL INSTITUTE OF HANDICAPPED RESEARCH (NIHR)

The National Institute of Handicapped Research funds research, training, and demonstrations at more than 100 educational institutions in both traditional and innovative fields of rehabilitation. UCPA continues to be concerned with the slow transfer of technology to the consumer. Much technology exists that could help disabled persons become employed and live more independently. Currently, NIHR is funding only one Rehabilitation Engineering Center (in Kansas) with a primary focus on employment issues.

UCPA urges the Committee to appropriate $49 million for NIHR in F.Y. 1987. This would include funding for a minimum of two new Rehabilitation Engineering Centers to demonstrate innovative models for the delivery of cost-effective rehabilitation engineering services to help meet the employment and independent living needs of individuals with severe handicaps.

JOB TRAINING PARTNERSHIP ACT

The Job Training Partnership Act (JTPA) provides employment training to persons with disabilities through the State Grant Program and through national projects funded by the Pilots and Demonstrations Account. Last year, seven national projects placed more than 5,000 individuals with disabilities in competitive employmemt. None of these seven projects focused their efforts on individuals with cerebral palsy. An increased funding level of this account would enable the Department of Labor to continue its support for the existing projects and initiate new demonstration projects.

UCPA is also strongly supportive of the state grant program. UCP affiliates in California, Maryland, Illinois and Connecticut are working closely with their local Private Industry Councils and providing critically needed vocational training and job placement services. However, nationwide UCPA is disturbed by the low percentage of individuals with disabilities who are being served by the Basic State Grant Program. Only 60,145 or 8.7% of the State Grant participants were identified as having disabilities during the 1984 program year.

UCPA joins CCDD in recommending $1.969 billion for the State Grant Program and agrees with the President's request for $40.7 million for the Pilot and Demonstration Account under Title IV. UCPA urges the targeting of a portion of the new dollars for a national project to serve persons with cerebral palsy.

DEVELOPMENTAL DISABILITIES STATE GRANT PROGRAM

The Developmental Disabilities State Grant Program provides funding to modify generic services or create specialized services to meet the needs of individuals with cerebral palsy and others with the most severe disabilities. UCP affiliates in ten states received funding during the past 24 months to demonstrate innovative housing, employment, or family-support service models that are now providing cost-effective alternatives to institutionalization.

The President has requested a 6% reduction from F.Y. 1986 appropriated levels for the State Grant Program. UCPA again joins with CCDD in recommending a modest increase to $56.5 million in funding for F.Y. 1987. These dollars will enable states to continue to make progress in assisting persons with developmental disabilities become more independent and productive in their home communities.

CONCLUSION

On behalf of UCPA, I want to thank the Subcommittee for providing us the opportunity to testify about federal programs that invest in human potential. Education, rehabilitation, job training and developmental disabilities programs provide opportunities for individuals with severe disabilitis to become more productive and self-sufficient. Only through these kinds of opportunities will our disabled citizens attain true independence and dignity.

WEDNESDAY, APRIL 30, 1986.

NICHD, NHLBI

WITNESS

DR. ROBERT DRESING, PRESIDENT, CYSTIC FIBROSIS FOUNDATION

Mr. **NATCHER**. Our next witness is Dr. Robert Dresing. Come around, Doctor.

Doctor, we will be pleased to hear from you. You have been before our committee on a number of occasions. We are glad to have you back.

Dr. **DRESING**. Thank you very much, Mr. Chairman. Appreciate the opportunity to come back again today.

We have submitted our testimony for the record and I am only going to take a couple of minutes to talk very succinctly about why we are here today.

Mr. **NATCHER**. Doctor, that would be really appreciated. We are running behind and when we get down to Dr. Albert Owens—is Dr. Owens in the room? When we get down to Dr. Owens, it will be probably long after the dinner hour.

Go right ahead. We are glad to have you.

Dr. **DRESING**. The news I bring is very good. I might tell you I am the President of the Cystic Fibrosis Foundation, but more importantly, the father of a child with the disease.

When we were before you, we were not aware of the gene for this disease and whether if it were, in fact, a single gene defect. In the past several months we have been able to locate the chromosome where the gene is and we have been able to eliminate it being more than a single gene defect.

Better news even than that is the fact we think we have a major clue as to how the gene is suppressing itself at the basic cellular level. Basically that means that we have a shot for the first time at being able to eliminate this disease.

We will not only be able to eradicate it from future generations, but the excitement that is going throughout the medical community today is the fact that we can alter the disease in those children who have it today.

My son is 20. Twenty-two is the average age for these children. The clock is running very fast for him. The excitement for us at thinking we have this kind of opportunity is indeed very, very great.

Your leadership over the years has been incredible for this Foundation and the fight out there this year is really going to be a tough one. We appreciate the fact that you have provided for us and for all of Congress an indication of where our priorities should be put.

We certainly understand budget cutting and we understand balanced budgets but we do not understand that at the expense of life for which we do not know a greater value that we would be making priorities that could come before that. Basically what our greatest fear is, Mr. Natcher, is that the children that have this disease today might possibly face death not as a result of having the disease but as a result of budget priorities or Gramm-Rudman.

That is intolerable for people who finally have a chance to make a difference in life against a tragedy like Cystic Fibrosis.

You have been terrific and your committee has been wonderful and we support you and will continue to support you. We are here asking today that the budget of $6.1 billion for NIH be the budget that is approved by Congress. Anything less is going to be a disaster.

We can't be satisfied with victories that are equated to only a little cut back or a holding the line because biomedical research today is exploding with opportunity for us to really impact the population.

Thank you for the opportunity to be here again this year. I hope when we come back next year the news may be even better and, if so, I might not have to come back anymore.

Thanks, Mr. Natcher.

Mr. NATCHER. Doctor, thank you very much. We appreciate your appearances. You have given us an excellent statement.

[The statement of Dr. Dresing follows:]

Cystic Fibrosis Foundation
(301) 881-9130
National Office
6000 Executive Boulevard • Rockville, Maryland 20852

TESTIMONY
OF THE
CYSTIC FIBROSIS FOUNDATION
BEFORE THE
SUBCOMMITTEE ON LABOR-HHS-EDUCATION APPROPRIATIONS
HOUSE APPROPRIATIONS COMMITTEE
REGARDING

FY 1987 APPROPRIATIONS FOR THE NATIONAL INSTITUTES OF HEALTH

Presented by:

Robert K. Dresing
President
Cystic Fibrosis Foundation

April 30, 1986
2:30 p.m.

Washington, D.C.

TESTIMONY OF THE CYSTIC FIBROSIS FOUNDATION BEFORE
SUBCOMMITTEE ON LABOR - HHS - EDUCATION
HOUSE APPROPRIATIONS COMMITTEE

April 30, 1986

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Mr. Chairman and Members of the Subcommittee:
My name is Robert Dresing, and I am president of the Cystic Fibrosis Foundation. I have been involved with the Foundation for nearly 18 years. Most importantly, I am the parent of a son with cystic fibrosis, the most common fatal genetic disease in the United States.

By approaching his twentieth birthday, Rob has already beaten many odds. He has lived substantially longer than most of the children with CF born in the early 1950's, who died before they reached kindergarten.

Rob is part of a new generation of children with cystic fibrosis who have survived long enough to become young adults. Nearly half of the children with CF today will live beyond age twenty-one. To do this, they must undergo rigorous physical and nutritional therapy every day. On top of these efforts, they try to pursue their educational, personal, and career goals.

Young adults like Rob know they are lucky to have survived this long. But we, their parents, face the daily reality that without new treatments or a cure, our children stand to face their twenties fraught with hospitalizations, repeated lung infections and finally death from respiratory complications.

The Cystic Fibrosis Foundation is an organization committed to changing that dread future with new treatments and a cure for this disease. We want to rid our country of CF, just as our children want to rid their lungs and digestive tract of the thick and clogging mucus that interferes with their breathing and digestion.

For our part, we have carefully designed our research program to meet NIH suggestions for encouraging the growth and quality of CF research. We are the first voluntary health organization to have ever launched a research center program that combined private and public funds. We have developed our own research centers, care centers, project grants, clinical trials and special grants. These efforts are not intended to either stand alone or duplicate NIH efforts, but rather to complement them. Many scientists who were initially funded by the Cystic Fibrosis Foundation are now receiving long-term NIH support. We have jointly sponsored conferences and studies with the NIH and have actually given the NIH funds for research.

These complementary efforts have led to rapid research progress. By sharing these exciting advances with you, I wish to underscore the need for keeping NIH funding a top priority and not destroying the groundwork that we have laid to solve CF.

For the first time in the 30 years since the CF Foundation was established, we have made impressive strides towards finding the gene that causes this inherited disease. In the last seven months, researchers have narrowed the search for the CF gene to less than one-tenth of one percent of the body's total DNA and established that this CF gene is located on chromosome 7.

A year ago, when our Foundation testified before you, we had no idea where the CF gene was located. All we knew was that researchers needed to find this gene before they could uncover its abnormalities. Recognizing this need, the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung, and Blood Institute (NHLBI) jointly sponsored a special request for applications.

The initial search for the CF gene among the body's four to six billion base pairs of DNA was like looking for a needle in a haystack. It meant systematically searching for markers, or tell-tale signs of DNA, that would indicate that the CF gene was nearby. And yet, by last October, two researchers supported by this joint NIDDK/NHLBI funding discovered such a marker, narrowing the search for the CF gene to a mere one percent of the body's entire DNA.

The next step was to find a marker even closer to the CF gene that would narrow the search even further. Here again, the diverse research funding of the NIH played a key role. At the NIH-sponsored Frederick Cancer Research Facility, Dr. George Vande Woude identified a marker on chromosome 7 in a research project unrelated to CF. He sent this marker to Dr. Raymond White at our Cystic Fibrosis Research Center at the University of Utah for additional testing. Dr. White, whose work is supported in part by the National Institute of General Medical Sciences (NIGMS), was able to establish that this marker from the Frederick Cancer Research Facility was within striking distance of the CF gene. His discovery has narrowed the search for the CF gene to one-tenth of one percent of the DNA.

This remarkable sequence of events could not have happened without the adequate and diverse NIH funding that allowed scientists supported by four different institutes to contribute to CF research progress in varied and extremely valuable ways.

The amazing pace of these last several months brings home the fact that cystic fibrosis is a disease that is finally ready to be solved. We have reached a point where the knowledge needed to conquer CF is developing right now. Today, cystic fibrosis is the frontrunner - we're stretching the genetic and cell technologies that will benefit not only our children but those with other diseases. The thirty years of slowly acquiring pieces of knowledge about cystic fibrosis are falling into place at last.

The next steps for CF research are clearer than ever before. While geneticists move in on the CF gene, other researchers can work on pinpointing how this gene affects the cells. Thanks to other NIH-supported research, we already have a clue -- salt has been found to move abnormally in and out of certain cells. Today, we can use the genetic and the cellular approaches to work from both ends towards conquering CF.

However, at this promising time, future research is being seriously threatened by the President's proposed 1987 budget and certain applications of the Gramm-Rudman law. While we respect the Congress' efforts to control the deficit, we ask that rather than implementing across-the-board cuts, the Congress exempt from Gramm-Rudman cutbacks the health programs so vital to our country's future. The grand opportunities offered by new genetic and cellular science mean we must maintain our priorities in health funding. It would be unfair to halt the very progress that is a result of our conscientiously laying the groundwork to promote the NIH's research possibilities.

Currently, the total NIH commitment to CF-related activities exceeds $12 million, largely allocated to the NIDDK and the NHLBI.

If the President's proposed budget for FY 87 is approved by the Congress, the NIH's noncompeting grants will be reduced by over 11% and new and competing grants by over 16%. The number of competing grants will fall to approximately 5100, with less than 30% of all study-section approved projects expected to be funded, meaning that many projects of high scientific merit would not be awarded.

Further, as the OMB increasingly dictates line item spending, the NIH is no longer able to choose the funding mechanisms most appropriate to the diverse stages and types of medical research. The negative impact of NIH's lack of control over funds can be seen in the limit placed on the number of research centers. Our own experience with eight Foundation-supported research centers is that they foster novel and multi-disciplinary research that cannot be captured in single project awards.

Also seriously threatened by both the cuts and control of funds is the NIH's own intramural program. This fine biomedical research program is a leader not only for this country but for the world.

As scientific knowledge burgeons, our country will need to fill the new void with well-trained scientists. The major cuts proposed for NIGMS training slots could damage our country's ability to meet future medical challenges.

It also appears that neither the NIDDK nor the NHLBI will be able to fund any of their planned clinical trials for FY 87 under the President's proposed budget. Additionally, the proposed cutbacks for General Clinical Research Centers (GRCCs) would limit the settings for clinical research. Without NIH support, many promising therapies that deserve clinical trails will be kept just out of the reach of the people who desperately need them.

As the parent of a child with CF, I strongly believe that I cannot ask others to help my child if I do not do everything in my own power to help him. But we as a Foundation know that our efforts alone cannot conquer this disease. Therefore, we support the recommendations of the Ad Hoc Group for Medical Research Funding. We recommend a funding level of $6.079 billion for the NIH. We emphasize the need for program balance at the NIH with a diversity of support mechanisms. We urge you to assure a high degree of flexibility in the management of the NIH for the best use of those funds. We also ask you to support growth in research career awards, research traineeships, clinical research projects and trials, and research centers.

Mr. Chairman, we finally know the path that future cystic fibrosis research must take. That in itself is a major accomplishment for which I thank you and the members of this Subcommittee. But even though the path is straight ahead, we will need adequate and diverse NIH funding to follow it. We are dependent on your leadership to ensure that the children who have survived this long will have the opportunity to benefit from the new treatments and cure which your thoughtful funding can bring to pass.

WEDNESDAY, APRIL 30, 1986.

CREUTZFELDT-JACOB DISEASE

WITNESSES

ANN PLUMMER, PARENT COUNCIL FOR GROWTH NORMALITY
LLOYD TATLOCK, PARENT COUNCIL FOR GROWTH NORMALITY
JANICE TATLOCK, PARENT COUNCIL FOR GROWTH NORMALITY

Mr. NATCHER. Our next witness is Ms. Plummer. I believe you have some other witnesses with you. We will be pleased to hear you.

Ms. PLUMMER. My name is Ann Plummer, a member of the Parent Council for Growth Normality, an organization of parents and health professionals that is concerned with the problems of short stature and growth delay.

For 20 years over 10,000 children were treated for growth disorders under the auspices of the National Pituitary Foundation, an agency funded under the National Institute of Diabetes and Digestive and Kidney Diseases.

In April of last year the unthinkable happened. Three young men who had taken growth hormones died of a rare and fatal disease, Creutzfeldt-Jacob Disease. Since the incubation of this disease—it may last for several decades—it was largely unheard of in people under 30 years of age.

A fourth case was later discovered in England. Since a known transmission method for C–J disease is through contaminated brain tissue, the link which is produced in the pituitary glands which have been harvested from cadavers was clear. Now, we live with the specter of C–J disease over our lives.

The course of the disease is rapid and devastating. Many people have likened it to Alzheimer's Disease in fast forward. It is essential for the future of our children that a long-term epidemiological study be conducted in which all of the recipients of human growth hormone be identified to be sure there aren't any cases of C–J disease that have remained undetected.

In addition, these individuals must be followed for a period of at last ten years due to the long incubation period of the disease. I wish to thank the committee for the support they have given this epidemiological study in the past and the report language accompanying the 1986 House appropriation bill.

I would like at this time to introduce to you the Reverend Lloyd Tatlock and Reverend Janice Tatlock, the parents of Wayne Tatlock, the first young man who died of C–J disease, who was also a human growth hormone recipient.

Mr. NATCHER. Delighted to have you before the committee.

Rev. JANICE TATLOCK. Thank you, Mr. Chairman. Our son Wayne died a helpless invalid of an undiagnosed disease on February 26, 1985. He was the oldest of our four sons. When he was eight or nine, our pediatrician in Jacksonville, Florida told us he had a form of dwarfism and suggested the best center for growth abnormalities in the country was at Johns Hopkins Hospital in Baltimore. He made arrangements for us to take Wayne there and after thorough tests, Wayne was accepted as a case study by the head of this program, Dr. Lawson Wilkins.

Wayne was one of the first group of children treated with the human growth hormone extracted from the pituitary gland of cadavers. We agreed that Wayne could be a case study because we felt he would have an opportunity to grow, that financially we as missionaries could not provide. He would be helping the doctors to provide growth through treatment for countless other children with similar growth deficiencies.

Wayne remained on this program throughout puberty. He was a warm and loving person with an outgoing personality and he led an active life. In March of 1984, he began to have a problem with his balance. It finally became so acute he was given medical leave from his place of employment and consulted first our general practitioner and then on his advice the neurologist.

Repeated tests and consultations revealed no abnormalities which was extremely discouraging to us. But his sense of balance became so poor that he progressed from a walker to a wheel chair. We took him to live with us so we could care for him and finally he could no longer feed himself or sit erect.

His speech at first became slurred and then almost unintelligible. The doctors told us they knew it was a degenerative neurological disease, but they were unable to pinpoint a diagnosis or a treatment.

There was nothing we could do for our son but to watch him die. On the morning of Wayne's death his jaws locked and we could not force the liquids that nourished him into his mouth. The nurse inserted a feeding tube through his nose so he would not dehydrate and he simply stopped breathing that night.

Shortly after Wayne's death, we learned that two other young men had died of similar symptoms and had been diagnosed as having C–J disease, a degenerative disease of the central nervous system that usually attacks only older adults.

What did these young men have in common? They had all been recipients of injections of the pituitary extract that we thought would save his life and increase his growth and they had all died of a virus carried by a diseased gland that produced Creutzfeldt-Jacob, a virus that lay dormant in Wayne over 15 or 20 years.

His condition was confirmed by post-mortem studies. We do not want to see other young men and women die as Wayne did. Neither do we want to see them denied their potential growth because they cannot receive the treatment that they need.

Our plea is that you grant the funds necessary so that research may continue. Our wish may become a reality and Wayne's death will not have been in vain.

The epidemiological study will require expenditure of $1.6 million initially and $10 million over the life of the study or the time necessary to complete it. That breaks down to approximately $100 per person annually.

Although progress has been made on the initial phases of the study, continuing funding is much dependent on the overall funding levels for the NIDDCD in the fiscal year 1987. It is just a drop in the bucket to what others have been asking, but it is a very important drop to us.

Thank you.

Mr. NATCHER. Thank you very much, Mrs. Tatlock. We want to thank you both, you and Reverend Tatlock, for appearing before our committee at this time and Ms. Plummer. You can rest assured that every consideration will be given to your request.

Thank you very much.

[The statement of the Parent Council for Growth Normality follows:]

TESTIMONY
of
MRS. DIANE C. COUSSAN
PRESIDENT
and of
JANICE AND LLOYD TATLOCK
PARENT COUNCIL FOR GROWTH NORMALITY

IMPACT OF APPROPRIATIONS
for
THE NATIONAL INSTITUTES OF HEALTH
on
GROWTH HORMONE DEFICIENT CHILDREN
HOUSE APPROPRIATIONS
SUBCOMMITTEE
on
LABOR, HEALTH AND HUMAN SERVICES,
AND EDUCATION
Wednesday, April 30, 1986
2:35 p.m.

I am Mrs. Diane C. Coussan, mother of a growth hormone deficient child, and president of the Parent Council for Growth Normality, a nationwide organization of families whose children require therapy with human growth hormone (hGH) for normal physical development. In the limited space and time provided, it is my intention to report on the crisis in the treatment of children with growth hormone deficiencies, the status of efforts to deal with this situation, and the necessity of seeking solutions within the context of appropriations to the National Institutes of Health.

In April of 1985, my family, along with approximately 12,000 others, was devastated by the suspension from distribution of pituitary-derived hGH following the deaths of three young men who had received hormone supplies produced and distributed by the National Hormone and Pituitary Program (NHPP), an agency funded under the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD). The deaths were linked to contamination of a still-undetermined number of hormone lots by Creutzfeldt-Jakob disease (CJd), a rare, degenerative, neurologic disorder for which there is no known treatment or cure.

In compliance with FDA requests, two commercial producers of pituitary hGH withdrew their products shortly thereafter, leaving all our children with no safe source of the treatment they desperately needed, and facing the specter of exposure to an incurable disease.

The impact of these events was heightened by the fact that most families, including my own, found that there was no coordination or agreement in information released to and by physicians, the FDA, or other official sources because of the serious lack of data on this disease in these circumstances.

As information gradually became available, the truly horrifying nature of our predicament became apparent. In seeking a more normal and fulfilling life for our children, by allowing treatment with a product represented as being safe, standard medical practice, we had unwittingly exposed them to a disease whose symptoms have been described as "Alzheimer's in fast-forward." With the onset of symptoms, there is a radid progression through erratic behavior, memory loss, difficulty in walking, loss of muscle control, and vision disturbances, to total helplessness and death, usually within a year.

To add to the nightmare nature of this disease, there is no diagnostic test for CJd, no method to indicate exposure or infection, until these symptoms occur. Often called a "slow virus," CJd can take up to twenty years to manifest itself after infection. There is presently no treatment or cure; CJd is always fatal. At this point, scientists lack sufficient data to say what amount of CJd slow virus, or over what period of time, would be required for the disease to develop in our children.

With the onset of the crisis, FDA and NIDDKD officials determined that two steps were necessary in assessing the nature of the risk to our children: inoculation of animals with as many lots of NHPP hormone as were available, and an epidemiological survey to identify and gather information on the health status of as many recipients of the hormone as possible. It is only through these methods that officials can 1)try to pinpoint infected hormone lots, and 2) determine how many other recipients may already have died from CJd as a result of these NHPP supplies. Compiling and analyzing this data is the only way to give an estimate of the risk of CJd death to the remaining hGH recipients.

Although the animal study is underway, the critical epidemiological survey remains in limbo. Epidemiology of this type is a basic prerequisite to the study of any disease. The extreme rarity of CJd in a young-adult population (and therefore the liklihood that it may be misdiagnosed), its long incubation period, the fact that NHPP pituitary hormone use stretches back over twenty years, and the lack of medical knowledge of the effects of low-dosage exposure over a period of years, all point up the necessity for this survey.

The survey, as proposed, will gather data on as many recipients of NHPP hormone as possible, to determine if there are any other, unreported cases of CJd in this group. Deceased patients will be cross-checked for cause of death. All living recipients will be followed over a period of several years to track any future CJd cases.

Despite scientific concensus on the necessity of this study, expressions of concern from Congress, and the passage of over a year since the crisis began, contracts required for project implementation, as well as funding commitments, have yet to be approved. To date, only "Phase 1" questionnaires have been sent to physicians. These were funded by money diverted from the suspended NHPP hormone distribution program, and required no external contracts. The physician surveys, although necessary to the body of data, were described by the Quarterly Report of the Public Health Service Interagency Coordinating Committee on CJd/hGH (September, 1985), as "...inadequate, by themselves, to ascertain all cases of CJd because the incubation period is so long that many patients will no longer be followed by their pediatricians during the time when CJd is likely to occur." (The three victims were in their twenties and early thirties.) The enormity of the task of locating recipients is compounded by the lack of methods to readily identify substantial numbers of patients from NHPP records.

Of further concern to our families is the present exclusion of commercially-supplied hormone recipients from the proposed survey. Although there have, as yet, been no deaths in this group, the long incubation period makes it unlikely that CJd has had sufficient time to manifest itself, if these supplies, with similar sterilization problems in terms of this disease, were also contaminated. It must be remembered that FDA concern was high enough to request the withdrawal of these products from the market, they have not been reinstated, yet their safety has yet to be addressed in terms of CJd risk.

By any reasonable standards, an inordinate period of time has passed without the implementation of the basic studies necessary to define the nature and extent of the risk to which our children have been exposed.

(5)

The longer full implementation is delayed, the greater the monetary and manpower costs become. FDA officials have confirmed that the three deaths which have already occurred could easily have been missed. Identification of recipients, particularly NHPP recipients going back to 1963, becomes steadily more difficult as time passes.

The "experiment"--inadvertent CJd transmission through hGH supplies--has already taken place. It would be extremely poor science, and a tragic waste of monetary and human resources, not to collect the data it provides. Epidemiological data forms the basis of such medical research. The medical-scientific community has stressed the unique opportunity to study an identifiable group exposed to a particular neurologic disorder, and the potential value of this research. Losing the opportunity to collect this data could seal the fates of future CJd victims, the majority of whom are not yet within the time frame for CJd symptoms to appear.

In calling for the immediate implementation of the epidemiological survey, we, as parents, look not only at what has already happened, but also to the future. We are aware that three years ago Dr. Carlton Gadjusek, Nobel Laureate and foremost authority on CJd, warned of the potential problem with hGH contamination. Had such a study been put in place then, how much further along might we be? Must we wait for three more years, or three more deaths, before this survey becomes a reality? Without this study we, and our children, can form no realistic estimates of CJd risk in our futures. We must live with the fear of this tragedy for the next twenty years, with no idea of the odds that it may strike our lives. With this study, we can make informed life decisions based on accurate knowledge of our risk, and may well find hope of a healthy future for our families.

The National Institutes of Health, specifically NIDDKD, is the proper agency to conduct this vital epidemiological survey. As the Institute responsible for endocrine disorders, they funded production and distribution of pituitary hGH through the National Hormone and Pituitary Program, which resulted in three deaths due to CJd contamination of those supplies.

It is only within a research structure such as that offered by the National Institutes of Health that the necessary potential for interdisciplinary cooperation and flexibility exists. The crisis facing our families overlaps into concerns involving the Institutes for neurology, child health, and mental health, among others. To their credit, NIDDKD has attempted to stimulate funding commitments among other involved agencies, but has met with little success.

A product produced and distributed under NIDDKD has killed three young men. NIDDKD is in a position to conduct the survey of the risk to 12,000 other young people. While the Parent Council is aware that the NIH appropriations are not line-item, strong report language can go a long way in expressing the will of the Congress and the people. On behalf of all our children, I urge you to express your support.

Our son, Wayne, died, a helpless invalid of an undiagnosed disease on February 26, 1985. He was the oldest of four sons. When he was only a baby, the doctors told us he wasn't growing as he should. They tried vitamin B 12 shots and thyroid treatment, but that didn't help.

When he was eight or nine, our pediatrician in Jacksonville, Florida, told us he had a form of dwarfism and suggested the best center for growth abnormalities in the country was at Johns Hopkins Hospital in Baltimore. He made arrangements for us to take Wayne there and after thorough tests he was accepted as a case study by the head of this program, Dr. Lawson Wilkins. He was one of the first group of children treated with the human growth hormone extracted from the pituitary glands of cadavers.

We agreed that Wayne could be a case study. He would have an opportunity to grow that financially we could not provide as missionaries for our church. And he would be helping the doctors to provide growth through treatment for countless other children with similar growth deficiencies.

Wayne remained on this program through puberty. He reached a height of four foot eleven inches. Unfortunately his system built up antibodies to the HgH. We never felt his treatment was a failure because we knew others were helped by what the researchers learned. Wayne also received psychological counselling to help him deal with his short stature. He was a warm and loving person with an outgoing personality, and led an active life.

In March of 1984, he began to have a problem with his balance. It finally became so acute, he was given medical leave from his place of employment, and consulted, first our general practicioner and then on his advice, a neurologist. Repeated tests and consultations revealed no abnormalities but his sense of balance became so poor that he progressed from a walker to a wheelchair. He came to live with us so that we could care for him. Finally he could no longer feed himself or sit erect. His speech at first became slurred, and then almost unintelligible. The doctors told us that they knew it was a degenerative neurological disease, but were unable to pinpoint a diagnosis or a treatment.

I repeatedly asked if it could be related to his growth problem, but they found no connection. I contacted Dr. Robert Blizzard, who had succeeded Dr. Wilkins on Wayne's case at Johns Hopkins to see if any of his other case studies had similar symptoms. He had recently completed a follow-up study of some of his former patients, and he said he had not heard of any one like Wayne at the time.

On the morning of Wayne's death, his jaws locked and we could not force the liquids that nourished him into his mouth. The nurse inserted a feeding tube through his nose so he would not dehydrate. He simply stopped breathing that night. We were glad he could die so peacefully.

Dr. Blizzard contacted us shortly after Wayne's death; two other young men had died of similar symptoms and had been diagnosed as having Creutzfeld-Jakob disease, a degenerative disease of the central nervous system that usually attacks only older adults. What did these young men have in common? They had all been recipients of injections of the pituitary extract and had died of a virus carried by a diseased gland that produced a disease called "Creutzfeld-Jakob", a virus that laid dormant in the gland for twenty or more years. HgH treatments were suspended until further studies could be made.

We do not want to see other young men and women die as Wayne did. Neither do we want to see them denied their potential growth because they cannot receive the treatment they need.

Our plea is that you grant the funds necessary so that research may continue so that our wish may become a reality.

Janice and Lloyd Tatlock
706 North 5th
Jacksboro, Texas 76056

(This is a copy of a letter to Dr. Robert Blizzard, Chairman of Children's Medical Center, University of Virginia, from Janice and Lloyd Tatlock, parents of Wayne Lee Tatlock, who died of the "Creutzfeld-Jabok" disease, February 26, 1985.)

Janice and Lloyd Tatlock
706 North Fifth Street
Jacksboro, Texas 76056
June 25, 1985

Dr. Robert Blizzard, Chairman
Children's Medical Center, U. of Virginia
Charlottesville, VA 22908

Dear Dr. Blizzard,

When my husband and I talked to you on the phone a few weeks ago, you asked us to write you about Wayne's illness from our point of view. I have done my best, even now I find that things that happened during his last few months of life that we thought we would never forget have begun to blur our momories. However, as best as I remember, here is how his illness progressed.

In early spring of 1984 (late February or early March) Wayne began to have a problem with his balance. He was not dizzy but he staggered slightly when he walked, and his hand trembled when he tried to lift a cup to his lips. It finally became so noticeable that he went to our family doctor, an internist in the Dallas Medical and Surgical Center, Dr. Mark Armstrong. Dr. Armstrong ran routine tests for inner ear problems, blood pressure change and other common causes of a similar nature. He also had an EKG done. All the tests came back showing no abnormalities, but his condition continued to worsen. Our doctor recommended that Wayne see a specialist, but he put it off until his company insisted he take a leave of absence for medical reasons. He had had some falls and had to hold on to walls and counters at work as he moved about. Wayne was the manager of a video department for a music store. Dr. Armstrong did talk him into going to Baylor Hospital for a brain scan and it came back normal.

In the latter part of April or the first of May (Wayne had driven out to see us in Jacksboro from Dallas a couple of times and we noticed his unbalanced walk with alarm) he went to see Dr. Ron Tintner, a neurologist at Southwestern Medical School and Parkland Hospital. Dr. Tintner was recommended to Wayne by a doctor who had been observing Wayne in the music store. Meanwhile, I went to see Wayne toward the end of May and found him in his apartment, on leave of absence again,not eating properly and not even leaving the apartment. He was seemingly unable to make decisions and letting his affairs go unattended. We took him to Jacksboro to stay with us and helped him arrange doctor's appointments in Parkland Hospital. He was admitted to Parkland on June 11 for more extensive tests. The results were the same as before. Everything checked out normal. But now he could only walk safely leaning on the arm of another person. All the doctors could say was that they might be able to diagnose his illness when it got worse. Wayne's cheerfulness was greatly affected and he became apathetic. He wouldn't ask questions or raise the issue of his illness with the doctors--seemingly resigned to his condition. (Summary of the hospitalization enclosed.)

We asked Dr. Tintner if it would be alright to take Wayne with us to Jamaica for the World Convention of Christian Churches the middle of July. At that time, we thought the trip would be good for Wayne. His condition worsened each day---tiredness, loss of balance, inability to make decisions. When we returned from Jamaica we closed out Wayne's apartment permanently and had him move in with us where we could care for him. I found that for several months he had regularly overdrawn his bank account and had to pay penalties although he had an adequate income. He had failed to pay his light bill and was in the apartment in May without lights. Apparently, some deterioration had been going on. We couldn't get him to verbalize satisfactorily in those months about his affairs and get him to become aware of what was going on. (Wayne always had a problem with "putting it altogether" and meeting regular schedules and commitments. He had vastly improved and was much better organized the year before his illness. His last job was fulfilling and he had a great attitude toward life and his condition during that time.)

Once we got Wayne home with us in August he seemed to cheer up and his mental attitude was good. There was no more apparent depression. He talked of his desire to return to work when he got better. His appetite was excellent and he gained a lot of weight as he was unable to exercise. During this time several of his friends travelled the hundred miles from Dallas to our home to visit him, and we included him in family activities as much as possible. Toward the end of August or first of September we had to use a wheel chair for he was not able to walk from the bedroom to the family sitting room. He was still continent but soon we had to use a urinary catheter. Dr. Tintner had him return to the hospital for NMR test, blood and thyroid studies in August. He told us that Wayne would develop tremors and that his legs would shake while sitting in the recliner where he came to stay most of the time. He could not bathe himself alone so his father and brothers would help him in the shower and later in the bathtub.

As his motor ability decreased, he began to use the walker and wheel chair more. As I mentioned above, we called Dr. Tintner several times and took Wayne in for consultations as an outpatient. Wayne saw Dr. Sachson, the endocrinologist, he had been seeing for several years for the last time in August.

On the night of October 31, we had to use the night pads for he could no longer control his bowels. On November 1, he was readmitted to the Parkland Hospital for further testing. He was confined to the wheel chair and could not stand along. He could barely feed himself now. His bowel and bladder control was unreliable. He was in the hospital for a week. (Discharge summary attached.)

When he came home he was using an external catheter and pads. His short-term memory was now obviously affected. From this point on (from the first of November) he had no interest in current events, family activities, etc. It was as if he were living in a hiatus between the past and the future. His long term memory was still good and apparently little affected as long as Wayne was mentally alert. Up until the last month he enjoyed playing Trivial Pursuit and was especially adept at answering Entertainment questions. He remembered to the end where he was and who he was, and recognized his family and friends. He spent his time watching television and had selected programs that he watched regularly. He lost his interest in music and didn't care to listen to tapes although his brothers bought him a Walkman. This surprised us as he had an extensive record collection and had always enjoyed all kinds of music. Some of his friends made special tapes for him that he listened to only once.

We arranged to have a hospital bed installed and rented a hydraulic lift so we could transfer Wayne from bed to wheel chair. He was able to sit up in the wheel chair for the family Christmas and even attended the Parish Christmas program the middle of December with the help of men carrying him. We found a lady who could come in and care for Wayne ten hours a week so that his father and I could get out some. Nurses from the Wichita Falls Home Health Center came in to give Wayne his testosterone injections and to make suggestions about how to care for him.

After Christmas chewing became so difficult for him that I began to process all of his food, and to feed him. His appetite had tapered off considerably and he lost some of the weight he had put on in August and September. In January he began to have difficulty swallowing and opening his mouth. His speech was greatly affected by now also. Occassionally he would choke on his food. We got a suction machine to use when needed.

After the first of the year he was confined totally to his bed. He appeared to be unaware of his body functions and no longer knew when he had soiled himself. He had little control of leg and arm movements. He couldn't hold a cup in his hands and get it to his mouth. We gave him daily massages and felt fortunate that he hadn't developed bedsores. He continued to grow weaker daily. (January-first of February, 1985) His speech was slurred.

From the middle of February we fed him ourselves. He couldn't talk but could still understand us and recognize us. The Parish elders brought him communion on Sunday, February 17 and asked him how he was. He was able to mutter "fine." He still recognized other friends and visitors as well.

On the morning of February 26 Wayne's eyes did not seem to focus and his jaw locked so that he could not open him mouth. We could not force it open to give him medicine. He began to run a fluctuating fever between 100-103 degrees which we monitored carefully. We called the nurse and after consulting with Dr. Berry, our local doctor, decided to insert a feeding tube to keep him from dehydrating. He was also breathing shallowly with a raspy sound and unable to articulate. The tube was inserted in the early afternoon and he was given antibiotics and tylenol for the fever. He rejected the liquid medicine. At six that night his father gave him some more medicine and liquids, per the nurses orders and made plans to sleep on a cot next to Wayne's bed. A little lafter ten on the night of February 26, just a few hours after the insertion of the feeding tube, his hands became cold and clammy (arms and other parts of his body as well). His axillary temperature was 101 degrees. His face became ashen and he simply stopped breathing without a struggle. We were by his bedside.

I certainly hope and pray that this write-up will prove to be helpful. Dr. Tintner has asked for our permission for a brain study on Wayne and we have given our permission. If we can be of further assistance, please feel free to call on us. We are deeply grateful to you, to the late Dr. Wilkins and those in the HgH program and feel a tremendous loss in this turn of events.

Cordially yours,

Jan Tatlock

JT/mh

WEDNESDAY, APRIL 30, 1986.

NIH

WITNESS

DR. JOHN NOBLE, BOSTON UNIVERSITY, REPRESENTING THE SOCIETY FOR RESEARCH AND EDUCATION IN PRIMARY CARE INTERNAL MEDICINE

Mr. NATCHER. Our next witness is Dr. John Noble. Come around, Dr. Noble. We will be pleased to hear from you.

Dr. NOBLE. Mr. Chairman, my name is John Noble. I am a Professor of Medicine at Boston University and the Director of the Primary Care Training Program in General Internal Medicine at the Boston City Hospital. I am testifying on behalf of SREPCIM.

SREPCIM was founded in 1978 as an affiliate of the American College of Physicians. Our major purpose is to promote the training of physicians in primary care or general internal medicine. Most of our members, who now number over 1200, serve on medical school faculties, and many are involved in the teaching of residents in general internal medicine.

Accordingly, SREPCIM is especially interested in the appropriation for training grants in general internal medicine and general pediatrics, and I will confine my remarks today to this aspect of the HHS budget.

Last year, thanks in very large measure to you and your committee, the Congress appropriated $18.5 million for training grants in general internal medicine and general pediatrics. This appropriation was reduced to 17.7 million dollars by the Gramm-Rudman sequestration in 1986. This cut led to a significant reduction in the number of funded programs that were in competitive cycles in 1986. Only five to six programs will be funded of the 32 proposals that were submitted this year.

These training programs have combined a remarkable training record. National surveys have recently showed 85 percent of all of the pediatric residents and 87 percent of all of the primary care general medicine residents have actually gone on to practice in primary care careers.

This is a very important career outcome and one which solidly supports the Federal sponsorship of this program.

Projections have been made regarding the nation's need for primary care physicians in the year 2000. It is clear that at that time 70 percent of all physicians should be primary care generalists and only 30 percent should be sub-specialists.

Thus, these primary care training programs, which this committee has strongly endorsed in the past, are a prototype for training physicians that will be most needed in the country in the years to come. Primary care training programs emphasize ambulatory care, continuing relationships and management of patients at home.

I have described this in some detail in my prepared testimony. This afternoon I would like to briefly direct your attention to three sort of special care problems which those of us who are the teachers of primary care doctors are facing today. These three problems include homelessness, AIDS and cost containment.

The epidemic of homelessness is one of the most pressing social problems throughout the United States today. In each of the Nation's 50 largest cities, medical and social resources are stretched to the limit to accommodate the needs of a continually increasing number of homeless people.

I serve on the National Advisory Board for a program sponsored by the Robert Wood Johnson Foundation and the Pew Memorial Trust, which is providing hands-on care to homeless people. What I have found in many cities is that the physicians and health care providers who are caring for homeless individuals are very often members of faculties of general medicine, pediatrics and family practice.

This group of highly motivated young physicians are providing service while also teaching their residents and students about the health care needs of this particularly needy group of our population. Take, for example, my second problem area, AIDS.

This second epidemic, Acquired Immune Deficiency Syndrome, is present throughout the Nation. It is obvious social interventions and health care programs are needed in all cities to provide care to individuals with AIDS infection.

In Boston we are presently developing a program that will provide coordinated services involving all hospitals and all clinics. Our city, like the other 50 major cities, are competing for funding for such a program.

It is interesting to find that while AIDS requires research and may benefit in the future from vaccines, today patients themselves need primary care physicians. Many of the young graduates of our primary care training programs in all States of the nation work in neighborhood health centers and inner-city practices.

It is these physicians who now more and more are being called upon to serve as the primary care givers to unfortunate patients afflicted with AIDS.

Cost containment is the third major issue facing our health care system. Primary care training programs I have learned throughout the country are stressing home care. The role of physicians in nursing homes and the care of patients with long-term illnesses, some of which we have heard about already in the hearing this afternoon.

As the American population ages, there will be a greater need for expertise in long-term care. Primary care training programs have taken the initiative both in general internal medicine and family practice to develop curriculum and to teach the best ways to take care of our older citizens.

Mr. Chairman, these are three problems that those of us who are teachers in the primary care field are trying to solve or work with while we are also training physicians to work with us. Considering the level of financial support for primary care training programs in general internal medicine and general pediatrics, I urge that your committee consider in 1987 that this is a transition year.

Long-term support for this type of medical education should clearly be included in the reimbursement system developed for physicians services and the national program to fund general medical education.

Unfortunately, there is no effective medicine now to support training in primary care or ambulatory settings under existing GME and existing physician reimbursement systems. These systems now are under intense review and will have to be radically revised and improved during the next one, two or three years if we are to reach our long term national training goals.

Primary care is a central component of our health care system. It will have to also be an integral part of the new methods developed to support graduate medical education. On behalf of the Society for Research and Education and Primary Care Internal Medicine, I urge that you consider funding general internal medicine and general pediatrics at the level of $18.5 million again this year.

This level of support will allow for the continuation of all federally approved programs and the many services and educational activities which these programs have developed to meet the nation's health care needs.

Mr. NATCHER. Thank you very much. Dr. Noble. We appreciate your appearance. You have made an excellent statement.

[The statement of Dr. Noble follows:]

Mr. Chairman, my name is John Noble. I am a Professor of Medicine at Boston University and the Director of the Primary Care Training Program in General Internal Medicine at the Boston City Hospital. I am testifying on behalf of SREPCIM.

SREPCIM was founded in 1978 as an affiliate of the American College of Physicians. Our major purpose is to promote the training of physicians in primary care or general internal medicine. Most of our members, who now number over 1200, serve on medical school faculties, and many are involved in the teaching of residents in general internal medicine. Accordingly, SREPCIM is especially interested in the appropriation for training grants in general internal medicine and general pediatrics, and I will confine my remarks today primarily to this aspect of the HHS budget.

Last year, you and your colleagues in the House appropriated $18.5 million for training grants in general internal medicine and general pediatrics. This appropriation was reduced to 17.7 million dollars by the Gramm-Rudman sequestration in 1986. This cut led to a significant reduction in the number of funded programs that were in competitive cycles in 1986. Only 5-6 programs will be funded of the 32 proposals that were submitted this year.

The 88 Primary Care Training Programs in General Internal Medicine and General Pediatrics are located mostly in the nation's major teaching hospitals. These hospitals train 80.5% of the resident physicians in American (Figure 1). Therefore, the Primary Care Training Programs are strategically located to have major impact on the training and development of young physicians.

The central purpose of the training grants in general internal medicine and general pediatrics is the support of a new kind of residency training, training which prepares young physicians to deliver high quality, cost-effective primary care services. Let me describe briefly the content of residency training in general internal medicine.

General internal medicine training differs from traditional internal medicine training in several important ways:

- More teaching occurs in an ambulatory setting. In a traditional internal medicine residency, about 10 percent of a resident's experience is in an ambulatory setting. In the general internal medicine programs supported by federal training grants, more than 25 percent of training takes place in such settings.

- General internal medicine programs emphasize continuity of care, as well as care which is comprehensive. Residents in these programs acquire skills in areas such as psychiatry, orthopedics, and gynecology, areas which are not part of traditional internal medicine training. Thus, they are able to manage the vast majority of problems encountered in ambulatory adult patients without referrals to subspecialists.

- Residents are taught principles of health maintenance. They work with other health professionals, including nutritionists and nurse practitioners, to counsel patients regarding diet, exercise, and other health-related behaviors. Thus, general internal medicine residents are able to help patients stay healthy as well as treat them when they are ill.

- General internal medicine training emphasizes cost-effective approaches to health care. Residents learn when to use laboratory tests as well as when not to use them. They also learn that many medical problems can be managed on an ambulatory basis, avoiding the need for expensive hospitalization.

- Perhaps most important, residents in these programs learn through experience and example that a career in primary care can be intellectually and personally rewarding -- and they stay with it. A recent SREPCIM survey of selected training programs shows that about 80 percent of residents trained in these programs choose careers in primary care. In contrast, only a third of the graduates of traditional internal medicine programs choose such careers. We currently are collecting more complete data on the training and career choices of residents in federally funded general internal medicine programs and will share this information with you as soon as it is available.

While the principal purpose of the training grants has been to support the education of general internal medicine residents, they have had other desirable effects. They have been a major stimulus to the development of divisions of general internal medicine throughout the United States. A 1984 SREPCIM study shows that there are now 145 divisions or sections of general internal medicine in U.S. medical schools. The faculty who staff these divisions play a critical role within their hospitals and medical schools:

- Faculty in divisions of general internal medicine spend almost half their time in direct patient care, usually in hospital-based clinics or group practices. These clinics are an important source of ambulatory care, especially for the poor. The presence of full-time faculty in such clinics has led to improvements in both the quality and efficiency of services.

- Faculty in divisions of general internal medicine spend about a third of their time teaching in ambulatory and inpatient settings. They supervise residents in traditional internal medicine programs as well as those in primary care. General medicine faculty train residents in health promotion and disease prevention, as well as cost-effective approaches to health care. Studies show that residents use hospital resources more efficiently when they are supervised by faculty in general internal medicine than when they are supervised by subspecialists.

- General internal medicine faculty serve as important role models for medical students, interns, and residents. Research indicates that medical school faculty have a significant influence on the career choice of physicians in training. The dominant role model on most medical school faculties is the subspecialist. The academic general internist offers trainees, including those in traditional internal medicine programs, an alternative.

The development of general internal medicine residency programs and faculty divisions of general internal medicine would not have been possible without federal grant support. Our current practices of paying physicians and hospitals encourage the development of faculties dominated by subspecialists and residency training programs focused on technology-intensive inpatient services. By explicitly funding ambulatory care teaching, the residency training grants have provided departments of medicine with an incentive to add to their ranks faculty interested in general medicine and residents whose training includes substantial ambulatory care.

In 1985, the leaders in general internal medicine, family practice, and general pediatrics jointly supported the reauthorization of the Health Manpower Training Acts. In doing so, they proposed that these programs develop three new initiatives for the next series of funding cycles. The first was to stress prevention. Primary care physicians must be trained to identify the vulnerable child, the problem family and the barely compensated adult, to intervene and to prevent illness and the varying combination of illness and tragedy.

B. To train physicians in community-based primary care settings. Doctors must become masterful managers of patient care in their communities if they are to not only meet acute and emergency needs but also to be able to prevent problems, and to effect social, environmental, and industrial changes to benefit their patients. Medical care is being moved out of hospitals.

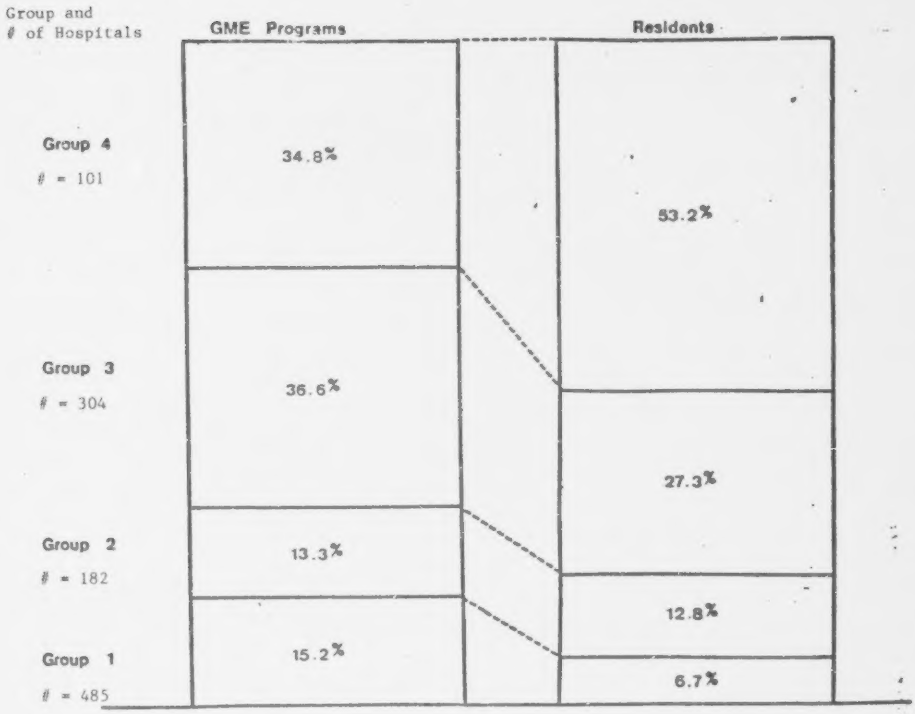
We are preparing physicians to practice less in the hospital, to use ambulatory surgery, to prevent unnecessary transfers from home to nursing homes and hospitals.

C. To teach principles of cost containment. If physicians are to practice effectively in community settings, they must be exposed to this type of practice during their training years. Only through such experience can young physicians learn how to manage patients in a cost effective manner utilizing community resources optimally to minimize reliance on hospitals or costly long term care facilities.

I had the opportunity to review all of the proposals that were submitted for competing extensions or new starts at the Division of Medicine in the Bureau of Health Professions during February of 1986. The programs which were proposed include almost uniformly these three new initiatives. Training programs in regional hospitals like the Scranton-Temple Training Program, training programs in both public hospitals like San Francisco General, and in private non-profit hospitals have all developed special educational experiences for young physicians to further this aspect of their medical education.

The career choices of pediatricians and internists graduating from these primary care residency programs have been studied carefully. National surveys have recently been completed which indicate that greater than 85 percent of all pediatric residents in primary care training programs supported by the Health Manpower Training Act are entering primary care practices. 87 percent of graduates of primary care general internal medicine practice also are entering primary care practices. This outcome of federal support is terribly important. Projections have been made regarding the nation's need for primary care physicians in the year 2000. It is clear that 70 percent of all physicians should be primary care generalists, and only 30 percent should be subspecialists. Unfortunately, particularly in the field of internal medicine at present, there is a disproportionate number of subspecialists being trained. The very small amount of federal support which has enabled these primary care training programs to develop is an excellent investment in the future of America's health care. These programs are training the types of physicians which are needed throughout the country. For that reason, we are requesting that the House Appropriations Committee mark up 18.5 million dollars to continue the support of primary care training in general internal medicine and general pediatrics. This level of support will allow all approved programs to be funded and also allow for the continuation of a special program in faculty development which could not be funded during 1986, but was approved and funded by the Congress in 1985. Faculty development is essential for the continuing improvement of primary care training.

CHART 1: DISTRIBUTION OF GME PROGRAMS AND RESIDENTS, BY HOSPITAL GROUP, 1979



WEDNESDAY, APRIL 30, 1986.

OSHA

WITNESS

JOHN C. BROOKS, COMMISSIONER OF LABOR, RALEIGH, NORTH CAROLINA

Mr. NATCHER. Our next witness is Mr. Brooks. We will be happy to hear from you.

Mr. BROOKS. Thank you very kindly, Mr. Chairman. I am delighted to be with you again this year. It is always a pleasure to visit before your Subcommittee on Labor, Health and Human Services and related agencies and today I would like to address the need for appropriations for Occupational Safety and Health Administration activities, and more specifically, Mr. Chairman, for the funding of State programs approved under Section 18 of the Occupational Safety and Health Act of 1970.

As the elected Commissioner of Labor for the State of North Carolina, I serve also as the State designee for our State occupational safety and health program.

There are presently 21 States and two territories with approved State plans for occupational safety and health covering both public and private sector employers and employees within their respective jurisdictions. Two additional States, Connecticut and New York, have approved plans applicable only to the public sector, with Federal OSHA retaining jurisdiction over private sector employers and employees.

According to the best available information that we have, North Carolina is the third largest jurisdiction with an approved State plan, both in number of covered workers and total population—excluding New York for total population since the New York plan is only applicable to the public sector.

Attached as exhibit one is a listing of the State plan jurisdictions, their population, the estimated number of covered workers, and the grant awards for fiscal years 1983, 1984, and 1985. We are told that the amounts awarded for fiscal year 1986 are the same amounts as fiscal year 1985 reduced by 4.3 percent, thus far.

In spite of the fact, however, that we cover more workers under our State plan than any other State program, other than California and Michigan, we rank only seventh in the amount of Federal funds allocated under Section 23(g) of the Occupational Safety and Health Act by the U.S. Department of Labor. Exhibit two ranks State plan jurisdictions by number of covered workers, and by Federal grant awards for fiscal years 1983, 1984 and 1985.

In 1978, the U.S. Court of Appeals for the District of Columbia ruled in AFL-CIO versus Marshall that the Occupational Safety and Health Act requires States to provide sufficient compliance personnel necessary for a "fully effective" program. In 1980, pursuant to this order, the U.S. Department of Labor established minimum benchmarks for field compliance personnel, both safety and health, that a State must achieve in order to be considered for final approval.

Only three small jurisdictions were able to receive final approval based upon these initial benchmarks. These are the Virgin Islands, Hawaii, and Alaska. These benchmarks have since been reevaluated and eight additional States have now received final approval based upon the revised benchmarks.

North Carolina participated in the revision process which resulted in our benchmarks being adjusted from 83 field safety compliance positions to 50, and from 119 field health compliance positions to 27.

We are currently still short 15 safety positions and 16 health positions, and this concerns us. The State of North Carolina is committed to having a fully effective State program. Workers in North Carolina deserve equal assurances of safe and healthful work places as do workers in other States.

The North Carolina General Assembly appropriated sufficient State funds—50 percent of the total cost—to allow us to add six safety and six health compliance officers effective July 1, 1985, and six more safety and six more health compliance officers effective July 1, 1986.

Our grant requests for fiscal year 1985 and 1986 included requests for Federal matching funds to provide the additional 50 percent of costs and to allow our staff to grow in size toward the newly revised benchmark figures established by Federal OSHA.

For fiscal year 1985, we requested $2,161,391, but received $2,053,052. This request would have enabled us to add 12 positions—six safety and six health--during the last quarter of fiscal year 1985.

We would still only have ranked sixth in the amount of Federal funds received for that year. For fiscal year 1986, we requested $2,770,353. Based upon the 1985 levels, this would have only moved us to fifth place in the amount of Federal funds received.

This increase would have funded 12 additional compliance positions—six safety and six health—for the entire year and 12 more new positions the last quarter of fiscal year 1986. We, however, have only been awarded $1,964,771 for fiscal year 1986.

At these similar appropriations hearings last year, statements were made by Federal OSHA representatives that State programs are being matched at a "level which will make them fully effective". Federal OSHA has promulgated revised benchmarks for North Carolina which speak to this level of effectiveness.

They, however, are not funding us at this level. Furthermore, at these same hearings, inferences were made that the States had not requested additional funds to meet the higher levels of personnel required, because they could not get matching funds from their own State legislatures. As indicated above, State funding for a total of 24 additional positions has already been allocated by the North Carolina General Assembly.

During the 1970s, Federal OSHA evidently approved whatever size grant requests were made to them. Some State programs grew in size more rapidly than others. Apparently, no effort was made to assure that an equitable distribution of funds was occurring. Then in the 1980s, as funds became more scarce, allocations to the States were made in proportions essentially equal to previous grants, rather than because of existing documented needs.

Section 23(g) of the Occupational Safety and Health Act states that, "The Secretary is authorized to make grants to the States to assist them in administering and enforcing programs for occupational safety and health contained in State plans approved by the Secretary pursuant to Section 18 of this Act.

"The Federal share for each State grant under this subsection may not exceed 50 percentum of the total cost to the State of such a program. In the event the Federal share for all States under either such subsection is not the same, the differences among the States shall be established on the basis of objective criteria."

References were made in last year's appropriations hearings to the establishment of an allocation formula. Then, Assistant Secretary Robert A. Rowland testified that Federal OSHA had ". . . been working on a formula to try to make the system more rational and equitable."

As yet we have not seen the results of this effort. In February the State designees by resolution asked the Assistant Secretary to appoint three people to work as a committee with three State representatives to try to establish a formula for a more equitable distribution of the funds for State programs. A copy of this resolution is attached as exhibit three.

Just last week, and since preparing this testimony, we have learned that this committee has been appointed.

Mr. Chairman, I have a list of that if you would like.

When faced with cuts for fiscal year 1986, instead of trying to allocate the existing Funds in a "rational and equitable" manner, each State program was cut an equal percentage. We realize that the cuts were to be applied equally to line items, but within the line item of State programs, discretion could have been applied so as not to doubly penalize a State that is already underfunded when compared to others.

We are not suggesting that the answer to this funding allocation problem is simple. We have, however, offered to Federal OSHA several suggestions for their consideration. One approach might revolve around the benchmark issue itself.

Assuming that these figures accurately reflect the particular needs of a State, then perhaps some correlation exists between them and the amount necessary to fund each State program.

Other approaches might utilize the number of workers covered by a particular State program. Still other factors might need to be considered and factored in, such as increased traveling expenses in a State like Alaska. Attached as exhibit four is a copy of four formulae submitted to the various other States and to Federal OSHA a year ago.

We are not here before you today to ask for exorbitant increases in OSHA funds or State program funds. As you carefully deliberate how best to appropriate funds for various programs, we would certainly caution you not to make cuts at the risk of our workers' safety and health, for this would ultimately only add costs to other programs. We would ask that you direct the U.S. Department of Labor to immediately commence allocating the funds appropriated to State programs in the most rational and equitable manner that can be devised, rather than to continue to reward a State simply based upon its ability to expend the funds allocated in previous years.

I thank you, Mr. Chairman, for the opportunity to continue this dialogue with the committee today.

[The attachments to the statement of Mr. Brooks follow:]

COMPARISON OF STATE PROGRAMS BY POPULATION, CIVERED WORKERS AND FEDERAL GRANT FUNDS

STATE ADMINISTERED PROGRAMS	POPULATION[2]	NUMBER OF COVERED WORKERS[3]	-FEDERAL GRANT FUNDS - FY 1983	FY 1984	FY 1985
REGION 1					
Vermont	529,868	200,000	418,864	451,189	454,623
Connecticut[1]	N/A	200,000	339,871	351,488	355,589
REGION 2					
Puerto Rico	3,389,686	608,707	1,410,771	1,768,426	1,546,752
Virgin Islands	101,500	35,410	200,084	229,520	235,414
New York[1]	N/A	1,100,000	N/A	820,373	1,830,000
REGION 3					
Maryland	4,347,666	1,500,000	2,360,845	2,326,231	2,428,912
Virginia	5,635,524	2,000,000	1,710,319	1,753,024	1,834,962
REGION 4					
Kentucky	3,722,606	1,300,000	1,745,479	1,976,634	2,066,768
North Carolina	6,163,772	2,300,000	1,844,811	1,951,603	2,053,052
South Carolina	3,300,712	1,500,000	1,121,969	1,200,965	1,257,729
Tennessee	4,715,080	1,800,000	1,096,155	1,172,573	1,297,383
REGION 5					
Indiana	5,495,702	1,958,300	1,697,738	1,903,270	1,992,059
Michigan	9,076,803	3,090,000	5,824,237	6,159,521	6,297,814
Minnesota	4,161,565	1,800,000	1,469,061	1,631,244	1,707,629
REGION 6					
New Mexico	1,424,509	470,000	437,980	596,699	581,053
REGION 7					
Iowa	2,910,894	1,051,100	753,671	753,671	790,038
Utah	1,650,972	560,000	743,142	794,244	832,462
REGION 8					
Wyoming	511,348	197,000	359,917	371,534	389,630
REGION 9					
Arizona	3,052,791	1,000,000	713,467	715,938	750,584
California	25,632,497	9,947,200	14,364,212	12,915,147	13,547,113
Hawaii	1,083,972	376,300	1,059,443	1,055,014	1,090,005
Nevada	910,978	454,700	755,959	707,494	734,408
REGION 10					
Alaska	411,897	195,000	950,634	1,055,681	1,082,945
Oregon	2,675,286	962,500	3,359,033	3,348,215	3,363,763
Washington	4,347,235	1,900,000	3,908,253	4,346,453	4,490,117

FOOTNOTES:

1. Connecticut and New York have state-administered occupational safety and health programs for their public sector establishments only.
2. 1984 estimate, based on U.S. Department of Commerce 1980 Census and 1984 growth and decline figures.
3. Derived from Fiscal Year 1985 State OSHA Grants.

RANKING	NUMBER OF COVERED WORKERS	- FEDERAL GRANT FUNDS -		
		FY 1983	FY 1984	FY 1985
1	California	California	California	California
2	Michigan	Michigan	Michigan	Michigan
3	North Carolina	Washington	Washington	Washington
4	Virginia	Oregon	Oregon	Oregon
5	Indiana	Maryland	Maryland	Maryland
6	Washington	North Carolina	Kentucky	Kentucky
7	*Tennessee	Kentucky	North Carolina	North Carolin
8	*Minnesota	Virginia	Indiana	Indiana
9	+Maryland	Indiana	Puerto Rico	Virginia
10	+South Carolina	Minnesota	Virginia	New York
11	Kentucky	Puerto Rico	Minnesota	Minnesota
12	New York	South Carolina	South Carolina	Puerto Rico
13	Iowa	Tennessee	Tennessee	Tennessee
14	Arizona	Hawaii	Alaska	South Carolin
15	Oregon	Alaska	Hawaii	Hawaii
16	Puerto Rico	Nevada	New York	Alaska
17	Utah	Iowa	Utah	Utah
18	New Mexico	Utah	Iowa	Iowa
19	Nevada	Arizona	Arizona	Arizona
20	Hawaii	New Mexico	Nevada	Nevada
21	*Vermont	Vermont	New Mexico	New Mexico
22	*Connecticut	Wyoming	Vermont	Vermont
23	Alaska	Connecticut	Wyoming	Wyoming
24	Wyoming	Virgin Islands	Connecticut	Connecticut
25	Virgin Islands	--	Virgin Islands	Virgin Island

* Indicates same number of workers

+ Indicates same number of workers

-- Indicates that New York did not have an approved plan for 1983

MOTION # 7:

Made by Mc Gowan of S.C.
Seconded by J. Brooks, N.C.

Motion to request U.S. OSHA to appt. 3 people to meet with 3 people to be appointed by the new chair of OSHSPA to work up a proposal for a fair distribution system for the distribution of federal OSHA funds to the several states; and requesting federal OSHA to allocate funds for use in contracting with an independent study organization for analyzing the problems and drafting proposals for such committees consideration.

Department of Labor
State of North Carolina
214 West Jones Street
Raleigh 27603

John C. Brooks
Commissioner

MEMORANDUM

TO: OSHSPA Members

FROM: John C. Brooks

DATE: June 17, 1985

RE: DISTRIBUTION FORMULA for Federal Appropriations for Operation of State OSHA Programs

You have previously received from me a copy of part of Bob Rowland's testimony before the House Committee on Appropriations' Subcommittee on Labor, Health and Human Services, Education and Related Agencies on April 1, 1985, wherein he states the federal OSH Administration's commitment to working out a fair distribution formula for the use of the federally apppropriated funds for support of state OSHA programs, his actions to achieve a consensus on such a formula in the past, and his request for state input into this effort in recent months. This is quite puzzling in light of reports made at the past several OSHSPA meetings, but it certainly indicates to us now the urgency and importance of our having direct in-put into the development of an appropriate formula.

Another copy of this transcript is enclosed for your review.

Also enclosed are reports showing the distribution of the available federal monies for each of the previous three years. Enclosed is data setting forth four proposed formulae for measuring the fairness of the distribution. Of course, it is fully realized that some states are not currently in a position to use any more money at this time even should more be made available to them. The object, however, is to establish a procedure whereby states know in advance of drawing up their proposals for budgeting for prospective fiscal years the amount of federal dollars available to them on a priority basis. Thereafter, those dollars not contracted for by entitled states would be available to other states in the same way that the $4,200,000 in returned, unused dollars are available to other states for use in any given fiscal year.

It is apparent from the several formulae considered that about 15% of the available funds are the subject of malapportionment concerns -- $8,000,000.

Formula I features the "benchmarks requirements. These benchmarks have not been recalculated for every state to date. Therefore, these benchmarks include those that have been recalculated, the actual authorized staff for states that have not recalculated their benchmarks, and, in some instances, actual authorized staffing rather than the recalculated benchmarks where the authorized staffing is higher than the recalculated benchmarks would provide. It is important to note that under this formulation each state is treated in accordance with its own actions to date. It is also important to note that the benchmarks are calculated only on a reflection of "high-hazardous manufacturing" in each state. The secretary does testify that current federal funding is adequate to enable every state to meet its benchmarks obligations. Therefore, there would seem to be a moral obligation to provide the money immediately to each state to enable it to do just that.

Formulae II and III reflect the number of workers in each state, minus those workers in the public sector, agriculture, and mining with the exception of three states where the figure represents those public employees specifically covered. While not very scientific or adequate, these two tables which are based upon 1979 and 1982 County Business Patterns data do serve to verify both what coverage each state claims and what level of responsibility each state bears to the whole, from data derived from a non-OSHA source. It is interesting for comparative purposes and to show the level of benchmarks that might be anticipated from those states which have not revised their benchmarks when they do get around to doing so.

Formula IV reflects the number of OSHA-covered workers in each state-plan state claimed by each state in its respective budget application filed with federal OSHA. This has the limitation that some of the figures are imaginatively calculated and rounded off and do not proportionately reflect their own benchmarks for some reason. Nevertheless, there is merit to the use of this formula in that it most accurately reflects the real obligations of the several programs in proportion to the whole and reflects the fair percentage of funds that might be anticipated to be claimed by those states that have not yet recalculated their benchmarks.

All of these formulae together affirm a certain amount of maldistribution which should be the immediate subject of action within the U.S. Department of Labor to correct. I propose that OSHSPA endorse a formula for the distribution of federally appropriated funds at its next meeting, and recommend that U.S. OSHA take steps to reapportion $2,000,000 during the 1986 fiscal year.

JCB/jc

Enclosures

STATE	CURRENT DISTRIBUTION OF FEDERAL MONEY	BENCHMARKS	FORMULA I	CHANGE LOSS	CHANGE INCREASE	NUMBER OF COVERED' WORKERS**	FORMULA II	CHANGE LOSS	CHANGE INCREASE
Alaska	$ 1,082,944	13*	$ 645,121	$ 437,823		106,266	$ 193,170	$ 889,774	
Arizona	846,722	15	744,370	102,352		758,086	1,378,050		$ 531,328
California	14,181,572	215*	10,669,305	3,512,267		8,073,586	14,676,179		494,607
Connecticut***	355,589	4*	198,499	157,090		161,200****	293,030	62,559	
Hawaii	1,090,005	27*	1,339,866		$ 249,861	303,092	550,961	539,044	
Indiana	2,117,983	70	3,473,727		1,355,744	1,876,369	3,410,867		1,292,884
Iowa	790,038	29	1,439,115		649,077	914,512	1,662,402		872,364
Kentucky	2,068,768	37	1,836,113	232,655		930,965	1,692,310	376,458	
Maryland	2,428,912	54	2,679,732		250,820	1,248,353	2,269,258	159,654	
Michigan	6,297,814	72*	3,572,976	2,724,838		3,080,584	5,599,891	697,923	
Minnesota	1,735,588	43	2,133,861		398,273	1,467,646	2,667,889		932,301
Nevada	734,408	17*	843,619		109,211	325,438	591,582	142,826	
New Mexico	581,053	28*	1,389,491		808,438	318,434	578,850	2,203	
New York***	1,830,000	38*	1,885,738		55,738	1,100,000****	1,999,582		169,582
North Carolina	2,053,052	77	3,821,100		1,768,048	1,953,574	3,551,210		1,498,158
Oregon	3,363,763	57*	2,828,606	535,157		840,712	1,528,248	1,835,515	
Puerto Rico	1,768,991	50*	2,481,234		712,243	435,433	791,531	977,460	
South Carolina	1,257,729	29	1,439,115		181,386	949,260	1,725,567		467,838
Tennessee	1,297,383	36	1,786,488		489,105	1,447,490	2,631,250		1,333,867
Utah	861,100	19	942,869		81,769	413,411	751,499	109,601	
Vermont	454,623	10*	496,247		41,624	159,619	290,156	164,467	
Virgin Islands	235,414	4*	198,499	36,915		40,829****	74,219	161,195	
Virginia	1,876,945	59	2,927,856		1,050,911	1,526,144	2,774,227		897,282
Washington	4,490,116	81*	4,019,598	470,518		1,250,088	2,272,412	2,217,704	
Wyoming	389,630	8	396,997		7,367	129,718	235,802	153,828	
Totals	$54,190,142	1092	$54,190,142	$8,209,615	$8,209,615	29,810,809	$54,190,142	$8,490,211	$8,490,211

Proposed distribution formulae for federal OSHA funds: $53,000,000 for Fiscal 1986 Budget, plus $4,600,000 Turned Back In (1984).

Formula I includes the minimum benchmark numbers for all states where recalculated, the current staffing positions for enforcement for all states which have not recalculated their benchmarks; and the actual staffing positions for enforcement for all states where recalculated but where the actual staffing positions number greater than those represented in the new benchmarks.

*Benchmark figures, based upon "high-hazardous manufacturing," which have not been revised since originally calculated.
**Department of Commerce 1979 County Business Patterns (Not including Public Sector, Mining, and Agricultural Workers).
***State plan coverage limited to public sector.
****FY'82 grant.

STATE	CURRENT DISTRIBUTION OF FEDERAL MONEY	NUMBER OF COVERED WORKERS++	FORMULA III	CHANGE LOSS	CHANGE INCREASE	NUMBER OF COVERED WORKERS+++	FORMULA IV	CHANGE LOSS	CHANGE INCREASE
Alaska	$ 1,082,944	122,386	$ 226,985	$ 855,959		195,000	$ 289,460	$ 793,484	
Arizona	846,722	809,230	1,500,848		$ 654,126	1,000,000	1,484,409		$ 637,687
California	14,181,572	8,311,358	15,414,759		1,233,187	9,947,200	14,765,709		584,137
Connecticut***	355,589	161,200+	298,971	56,618		200,000	296,882	58,707	
Hawaii	1,090,005	308,924	572,950	517,055		376,300	558,583	531,422	
Indiana	2,117,983	1,671,162	3,099,441		981,458	1,958,300	2,906,917		788,934
Iowa	790,038	833,084	1,545,089		755,051	1,051,100	1,560,262		770,224
Kentucky	2,068,763	875,998	1,624,680	444,088		1,300,000	1,929,731	139,037	
Maryland	2,428,912	1,268,349	2,352,359	76,553		1,500,000	2,226,613	202,299	
Michigan	6,297,814	2,617,941	4,855,396	1,442,418		3,090,000	4,586,823	1,710,991	
Minnesota	1,735,588	1,422,215	2,637,728		902,140	1,800,000	2,671,935		936,347
Nevada	734,408	334,663	620,687	113,721		454,700	674,961	59,447	
New Mexico	581,053	330,762	613,452		32,399	470,000	697,672		116,619
New York***	1,830,000	1,100,000+	2,040,128		210,128	1,100,000	1,632,849	197,151	
North Carolina	2,053,052	1,952,560	3,621,339		1,568,287	2,300,000	3,414,140		1,361,088
Oregon	3,363,763	762,592	1,414,350	1,949,413		962,500	1,428,743	1,935,020	
Puerto Rico	1,768,991	413,156	766,269	1,002,723		608,707	903,570	865,421	
South Carolina	1,257,729	959,885	1,780,258		522,529	1,500,000	2,226,613		968,884
Tennessee	1,297,383	1,393,529	2,584,525		1,287,142	1,800,000	2,671,935		1,374,552
Utah	861,100	420,838	780,512	80,588		560,000	831,269	29,831	
Vermont	454,623	161,817	300,116	154,507		200,000	296,882	157,741	
Virgin Islands	235,414	40,829+	75,724	159,690		35,410	52,563	182,851	
Virginia	1,876,945	1,563,729	2,900,189		1,023,244	2,000,000	2,968,817		1,091,872
Washington	4,490,116	1,237,317	2,294,805	2,195,311		1,900,000	2,820,376	1,669,740	
Wyoming	369,630	144,815	268,583	121,047		197,000	292,428	97,202	
Totals	$54,190,142	29,216,339	$54,190,142	$9,169,691	$9,169,691	36,506,217	$54,190,142	$8,630,344	$8,630,344

Proposed distribution formulae for federal OSHA funds: $53,000,000 for Fiscal 1986 Budget, plus $4,600,000 Turned Back In (1984).

+FY'82 grant.
++Department of Commerce 1982 County Business Patterns (Not including Public Sector, Mining, and Agricultural Workers).
+++From current State OSHA Budget Applications.
***State plan coverage limited to public sector.

WEDNESDAY, APRIL 30, 1986.

DOL PROGRAMS

WITNESS

MICHAEL URQUHART, AFGE-LOCAL 12

Mr. NATCHER. Our next witness is Mr. Urquhart. We will be glad to hear from you.

Mr. URQUHART. Thank you, Mr. Chairman.

I want to thank you for allowing me to come back this year and testify on the Department of Labor's budget.

My name is Michael Urquhart. I am appearing before your committee on behalf of the American Federation of Government Employees, Local 12, which represents 5,000 Department of Labor employees in the Washington metropolitan area.

I would like to thank you for the support you have shown for our programs in the past and especially last year when many of the same cuts proposed for this year were deleted from the budget and those programs were funded. I want to thank you for that support and other members of the committee.

The proposed budget for fiscal year 1987, which provides funding at a level roughly equivalent to the two previous years, is clearly not sufficient. Numerous studies, congressional hearings, and reports have detailed the weaknesses in the Department of Labor's programs, including enforcement of ERISA, health and safety standards and regulations, Fair Labor Standards Act, and Black Lung and Workers Compensation programs.

The impact of five years of budget cuts, reducing the Labor Department's budget 50 percent and employees 25 percent, can be seen in the recent statistics on occupational injuries and illnesses. After declining from 1979 through 1983, the number of work-related injuries and illnesses rose 11.7 percent in 1984, the last year for which data is available today.

This represented an increase of half a million injuries and illnesses, half a million people who have suffered because OSHA lacks the resources to guarantee every American a safe and healthy work placc.

The Labor Department has also been adversely affected by the mindless Gramm-Rudman-Hollings cuts required in fiscal year 1986. The 4.3 percent reduction has been concentrated in personnel costs. Furloughs in some agencies are anticipated. Training has been postponed or canceled.

Transfers and reassignments are widespread. And a general sense of turmoil exists that disrupts all programs. The possibility of even more substantial Gramm-Rudman-Hollings cuts in fiscal year 1987 has caused fear among all employees, and reduced their morale and productivity.

I would like to turn now to some of the specific proposals.

Last year the Administration proposed the elimination of the Job Corps program. They argued that the program was expensive and inefficient, and that its goals could be achieved through the Job Training Partnership Act. This argument was rejected by both houses of Congress.

This year they propose a 45 percent cut from the fiscal year 1986 level. The justification for this cut remains the same, and should be similarly rejected.

Funding at the proposed level will provide only 22,000 training slots, compared to the previous 40,000. No one has argued that there is not a need for a full Job Corps program. Nor can other programs, such as JTPA, make up the difference.

The Administration is proposing the elimination of the least cost effective Job Corps centers. This only makes the disadvantaged youths suffer for management mistakes. The Department of Labor has the tools to take action against ineffective and poor management of the centers. If contractors do not take corrective action, and if their performance remains below standard, then their contract is not renewed and the contract can be given to someone else.

This type of forceful management can reduce the cost of the Job Corps, while continuing to provide for 40,000 training slots.

While the Administration continues to profess a desire to get people off welfare, it is once again proposing to eliminate the Work Incentive Program, which is one of the few programs which has been successful in achieving that goal.

Many of the successful State programs, such as California's Greater Avenues for Independence and Massachusetts' ET Choices depend on the WIN program for funding. Indeed, as the American Public Welfare Association has noted, the "WIN program is currently the single Federal strand holding together the States' innovative welfare employment programs."

As Governor Dukakis has noted, "It is penny-wise and pound-foolish to cut these funds. This program represents a tremendous opportunity to break the welfare cycle and help welfare recipients become tax-paying members of society."

In Massachusetts alone, the program there has saved the Federal Government over $70 million.

The Administration is again proposing elimination of the Mass Layoff-Plant Closing program. Any thoughts that this program was no longer necessary in the current economic climate was given a rude shock when the unemployment rate surged upwards, and massive layoffs hit the oil industry.

In spite of the continual political and budgetary problems afflicting this program, progress was made in fiscal years 1985 and 1986. To date, 43 States and the District of Columbia are committed to the program.

For the first time, the United States would have the information necessary to quantify the complex problem of plant closings and the resulting unemployment and underemployment. The statistical information generated could be important in understanding the need for UI, trade adjustment assistance, plant closing legislation and training programs like Job Corps and JTPA.

This program has generated broad support. State and local governments, private research organizations, business and labor organizations are all interested in the plant closing and dislocated worker information. There is currently no other source for information of this type at this level of industry/area detail.

Local 12 also urges continued funding for Professional, Administrative, Technical and Clerical Pay (PATC) survey. Although an expansion of PATC is called for in the President's budget, we understand that there has been some consideration of cuts to this program and possibly its elimination entirely.

We believe that PATC is an important program. The PATC survey is the basis for pay comparisons under the Federal Pay Comparability Act of 1970 and is the best means available of judging where Federal employee pay is in relation to other sectors.

It is also the only data available on such important occupational groups as accountants, attorneys, chemists, engineers, computer programmers, system analysts, clerical workers and other occupations which are playing an increasing role in the economy. In addition, PATC is used by government agencies to estimate labor costs for proposed contracts.

In summary, Federal employees understand that action must be taken to reduce the Federal budget deficit. We know this means that tough decisions must be made. But we cannot endorse budget actions which threaten the health and welfare of America's working people, and which make it difficult if not impossible for the Department of Labor to accomplish its mission and function.

Nor does it make sense to eliminate programs in the name of fiscal responsibility that have proven themselves to be cost effective, and actually save the government money at the Federal, State, and local level.

I, therefore, urge this committee to reject the Administration's proposals to eliminate the WIN and Mass Layoff/Plant Closing programs, to reduce the Job Corps, and to freeze funding for other Department of Labor programs at inadequate levels.

Thank you very much.

Mr. NATCHER. Thank you, Mr. Urquhart. You have made an excellent statement and we appreciate your appearance.

[The statement of Mr. Urquhart follows:]

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STATEMENT OF

MICHAEL URQUHART
PRESIDENT, LOCAL 12
AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES
AFL-CIO

BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES
AND EDUCATION APPROPRIATIONS
OF THE HOUSE APPROPRIATIONS COMMITTEE

ON

THE U.S. DEPARTMENT OF LABOR'S APPROPRIATION FOR FY87

ON

APRIL 30, 1986

I welcome this opportunity to testify on the Department of Labor's budget request for fiscal year 1987. My name is Michael Urquhart. I am appearing before your committee on behalf of the American Federation of Government Employees, Local 12, which represents 5,000 Department of Labor employees in the Washington metropolitan area.

The Department of Labor was established to promote the welfare and working conditions of working people in this country. Clearly, it cannot fulfill that mission if it is denied the resources to carry out the programs that have been developed over the years and mandated by Congress. The proposed budget for FY 87, which provides funding at a level roughly equivalent to the two previous years, is clearly not sufficient. Numerous studies, Congressional hearings, and reports have detailed the weaknesses in the Department of Labor's programs, including enforcement of ERISA, health and safety standards and regulations, Fair Labor Standards Act, and Black Lung and Workers Compensation programs.

We understand the budget problems facing Congress this year. But we cannot, in good conscience, sit idly by while Department of Labor programs are inadequately funded, and when the lack of enforcement increases the danger to the health and safety of every American. If the job is worth doing, we have always been told, it is worth doing well.

The impact of 5 years of budget cuts, reducing the Labor Department's budget 50 percent and employees 25 percent, can be seen in the recent statistics on occupational injuries and illnesses. After declining from 1979 through 1983, the number of work-related injuries and illnesses rose 11.7 percent in 1984, the last year for which data is available today.

This represented an increase of half a million injuries and illnesses, half a million people who have suffered because OSHA lacks the resources to guarantee every American a safe and healthy workplace.

The Labor Department has also been adversely affected by the mindless Gramm-Rudman-Hollings (G-R-H) cuts required in FY86. The 4.3 percent reduction has been concentrated in personnel costs. Furloughs in some agencies are anticipated. Training has been postponed or cancelled. Transfers and reassignments are widespread. And a general sense of turmoil exists that disrupts all programs. The possibility of even more substantial G-R-H cuts in FY87 has caused fear among all employees, and reduced their morale and productivity.

The continual budget upheaval, where programs are proposed for elimination, and then later given funding, or where cuts are made in mid-fiscal year, only to be restored in the next fiscal year, makes effective management of these programs extremely difficult and long range planning impossible.

I would like to turn now to some of the specific proposals in the Department's budget request for FY 87.

1. REDUCTION OF THE JOB CORPS.

Last year the Administration proposed the eliminantion of the Job Corps program. They argued that the program was expensive and inefficient, and that its goals could be achieved through the Job Training Partnership Act (JTPA). This argument was rejected by both houses of Congress.

This year they propose a 45% cut from the FY86 level. The justification for this cut remains the same, and should be similarly rejected.

Funding at the proposed level will provide only 22,000 training slots, compared to the previous 40,500. No one has argued that there is not a need for a full Job Corps program. Nor can other programs, such as JTPA, make up the difference. JTPA was never designed to reach the population that the Job Corps does -- disadvantaged youths with little prospect of employment.

The administration is proposing the elimination of the least cost effective Job Corps centers. This only makes the disadvantaged youths suffer for management mistakes. The Department of Labor has the tools to take action against ineffective and poor management of the centers. If contractors do not take corrective action, and if their performance remains below standard, then their contract is not renewed and the contract can be given to someone else.

This type of forceful management can reduce the cost of the Job Corps, while continuing to provide for 40,000 training slots.

The Department of Labor also does not consider the cost of closing the centers. Thirty of the centers are part of the Civilian Conservation Corps, and are staffed by Federal employees. Any shutdown would result in Reductions in Force with all the disruption and added costs that we have learned are associated with such actions.

In the final analysis, reduction or eliminantion of the Job Corps simply does not make fiscal sense. In spite of all the Administrations attempts at justifications for its actions, no one has challenged the results of the Mathematica Study which showed that the Job Corps returns $1.46 for every $1.00 spent.

Previously, the Labor Department had characterized the program as "the last, best hope to join the societal mainstream" for the youth that it serves. With youth unemployment at about 18 percent, and the jobless rate for black youth over 40 percent, the Job Corps is a beacon of hope. Don't take away that hope.

2. WORK INCENTIVE PROGRAM (WIN)

While the Administration continues to profess a desire to get people off welfare, it is once again proposing to eliminate the Work Incentive Program (WIN), which is one of the few programs which has been successful in achieving that goal. Unfortunately, the Senate budget committee has also endorsed this proposal.

WIN has proven itself as a cost effective program that has demonstrated its ability to assist AFDC recipients and applicants to find unsubsidized employment. Approximately 75% of those served are single mothers who would not be assisted by JTPA. The $165 million budget of the WIN program is less than half of what the program saved last year in lower AFDC payments.

Many of the successful state programs, such as California's Greater Avenues for Independence (GAIN) and Massachusetts' ET Choices depend on the WIN program for funding. Indeed, as the American Public Welfare Association has noted the "WIN program [is] currently the single federal strand holding together the states' innovative welfare employment programs."

The Massachusetts program has resulted in a cut in the welfare caseload from 93,000 to 84,000 families, at a saving to the state and federal governments of about $70 million.

As Governor Dukakis has noted, "It's penny-wise and pound-foolish to cut these funds. This program represents a tremendous opportunity to break the welfare cycle and help welfare recipients become tax-paying members of society." (Boston Globe 2/5/85)

3. ELIMINATION OF THE MASS LAYOFF/PLANT CLOSING PROGRAM

The Administration is again proposing elimination of the Mass Layoff-Plant Closing program. Any thoughts that this program was no longer necessary in the current economic climate was given a rude shock when the unemployment rate surged upwards, and massive layoffs hit the oil industry.

Inspite of the continual political and budgetary problems afflicting this program, progress was made in fiscal years 1985 and 1986. In addition to the 8 states in ongoing production status, 32 new states and the District of Columbia finalized cooperative agreements with BLS in FY85, and 3 more states were added in FY86. To date, 43 states and the District of Columbia are committed to the program.

The mass layoff-plant closing program will provide the first truly comprehensive statistics on plant closings and their impact on laid off workers. Information generated would include the number of firms, the number of effected workers and the number of workers staying on Unemployment Insurance (UI) by state, industry and by reasons for layoff. Furthermore, a statistical sample of those who received final UI payments would be tracked for subsequent employment experience.

For the first time, the United States would have the information necessary to quantify the complex problem of plant closings and the resulting unemployment and underemployment. The statistical information generated could be important in understanding the need for

UI, trade adjustment assistance, plant closing legislation and training programs like Job Corps and JTPA.

This program has generated broad support. State and local governments, private research organizations, business and labor organizations are all very interested in the plant closing and dislocated worker information. There is currently no other source for information of this type at this level of industry/area detail.

4. CONTINUATION OF THE PATC SURVEY

Local 12 urges contined funding for Professional, Administrative, Technical and Clerical Pay (PATC) survey. Although an expansion of PATC is called for in the President's budget, we understand that there has been some consideration of cuts to this program.

We believe that PATC is an important program. The PATC survey is the basis for pay comparisons under the Federal Pay Comparability Act of 1970 and is the best means available of judging where Federal employee pay is in relation to other sectors. It is also the only data available on such important occupational groups as accountants, attorneys, chemists, engineers, computer programers, system analysts, clerical workers and other occupations which are playing an increasing role in the economy. In addition, PATC is used by government agencies to estimate labor costs for proposed contracts.

SUMMARY

Federal employees understand that action must be taken to reduce the Federal budget deficit. We know this means that tough decisions must be made. But we cannot endorse budget actions which threaten the health and welfare of America's working people, and which make it difficult if not impossible for the Department of Labor to accomplish its mission and function.

Nor does it make sense to eliminate programs in the name of fiscal responsibility that have proven themselves to be cost effective, and actually save the government money at the Federal, State, and local level.

I, therefore, urge this committee to reject the Administration's proposals to eliminate the WIN and Mass Layoff/Plant Closing programs, to reduce the Job Corps, and to freeze funding for other Department of Labor programs at inadequate levels.

WEDNESDAY, APRIL 30, 1986.

ANIMAL RESEARCH

WITNESS

DR. MURRY COHEN, MEDICAL RESEARCH MODERNIZATION COMMITTEE

Mr. NATCHER. Our next witness is Dr. Cohen. Come around, Doctor. We will be pleased to hear from you at this time.

Dr. COHEN. Thank you. Mr. Chairman, members of the subcommittee, thank you for the opportunity to testify here today concerning the appropriations for the National Institutes of Health for fiscal year 1987.

My name is Murry Cohen, and I am an M.D. specializing in psychiatry. I am currently engaged in the private practice of psychiatry, and I serve as the Chief of the Psychiatry Out-Patient Department of a New York City teaching hospital.

Formerly, I was the Director of the Narcotics Rehabilitation Center of another New York teaching hospital. Finally, I am a member of and represent the Medical Research Modernization Committee, a group of approximately 800 health care professionals, including physicians, dentists, veterinarians, psychologists, nurses, social workers, researchers, and other clinicians and PhDs of various types.

In my remarks today, I will first address three general areas of research which are funded by the Federal Government and from which no significant medical knowledge is gained, provide an example of waste NIH funds and discuss a new program proposed by NIH which has not been adequately justified and would squander taxpayers' money.

The Medical Research Modernization Committee believes that the "animal model" idea of research into human diseases and behavioral problems has been largely rendered obsolete by the tremendous advances in radiology, laboratory and computer sciences and cell and organ culture techniques.

Such new research methods make it possible to study noninvasively human beings, human cells and human organs directly. Obviously, data obtained from human study are directly relevant to humans, whereas data obtained from "animal model" studies are often irrelevant, wasteful, redundant and a hindrance rather than an aid to progress.

Old ways of doing research and outmoded methods continue on their own inertia and the animal model idea of research is no exception. Examples of such outmoded research include three prime categories.

First, human addiction problems including alcohol, drugs and smoking. Thousands upon thousands of papers clutter the literature and are still being turned out. It is relatively easy to take a group of mice, dogs, monkeys or other species and to subject them to cocaine, LSD, cigarette-smoking, alcohol and then to describe the results. In the considered opinion of our committee, such studies are irrelevant to humans, often redundant and give the false impression that human problems are being studied scientifically.

A second area of waste of tax dollars is that of psychiatric illness and studies of human behavioral problems. One notorious example is that of Harry Harlow who about 40 years ago began writing papers describing the damage done to baby monkeys by depriving them of mothering and by confining them in isolation chambers he termed "wells of despair". These projects continue to be tax funded at universities as well as on the premises of the National Institutes of Health.

Our committee members agree that this work is more a comment on human insensitivity than anything else. Such projects have no relevance to depression in humans. In addition, efforts to create a schizophrenic or crazy animal model are equally irrelevant.

The third area in which research on animals is a waste of time and tax dollars is that of impact and trauma studies, including such disasters as gunshot and other wounds, electrocution and radiation, car crashes and the like. These have long ago reached a point of overkill where nothing new is added to already existing knowledge.

Our committee urges the Congress to facilitate modernization of research by withholding appropriations for outdated animal model research for proper research and, we favor research in which human and behavioral problems are studied directly since modern advances in technology and equipment make this possible in a safe, non-injurious way with informed and consenting human subjects.

An example of waste of NIH funds is the $30,000 per year being spent to house the 15 Silver Spring monkeys which have been experimented on and badly mistreated by the researcher. These primates, removed from the laboratory that mistreated them, are not currently part of a research protocol, but are cruelly being kept captive by NIH because of pressure from the biomedical research community to further entrench the notion of animal experimentation.

These animals have suffered enough and humane organizations are willing to assume responsibility for these animals and transfer them to a primate sanctuary in Texas. In spite of assurances from NIH that these pathetic monkeys would be transferred to a humane organization, the Institute for Behavioral Research has prevented this transfer.

Congressmen Smith and Rose are desperately trying to facilitate the proper and humane disposition of these animals as originally promised by NIH by circulating a letter that has already been signed by 120 Congressmen.

Mr. Chairman, it is not right to continue to keep these maimed and suffering creatures captives of lobby groups. I implore the members of this subcommittee to aid Congressmen Smith and Rose in their efforts and work to protect and speak for previously abused primates who cannot speak for themselves.

The National Institutes of Health is proposing to begin yet another new program in fiscal year 1987 which will further perpetuate the scientific community's reliance on models. According to an article in the March 27, 1986 issue of New Scientists and other NIH documents, the NIH is proposing to begin a National Chimpanzee Breeding program in 1987. The cost of this program has been estimated at anywhere from $17 million to $2 billion.

The NIH has not specifically requested any funds for implementation of the program. Our committee considers this program to be a waste of taxpayer's money in these austere economic times.

Chimpanzees are used in three major research areas: non A-non B hepatitis, AIDS, and organ transplant surgery. In the first two instance the animals, although able to produce antibodies to the pathogenic organism, do not develop the clinical syndrome. With regard to non A-non B hepatitis, since chimpanzee research has proven to be unyielding of results which are therapeutic to man, one wonders why it is pursued.

With regard to AIDS, Dr. Robert Pollack, a dean at Columbia University, in his effort to initiate a national effort to develop a vaccine to counteract the disease, wrote in the New York Times, November 25, 1985, "there are no animals suitable for initial testing of a vaccine . . .", and "in the absence of an animal model for AIDS, such vaccines could not be tested on volunteers, because government regulations require that new vaccines be first tested in an animal."

Thus it appears that the use of chimpanzees in AIDS research actually impedes progress, given the huge population of potential human volunteers.

The Medical Research Modernization Committee respectfully asks that this committee consider that roughly one-half of each of each dollar spent on research is used for studies of models of humans and not on studies directly helping humans. This trend must be reversed if we are to efficiently advance our knowledge of human behavior and disease. We ask that this committee review the egregious waste of tax dollars by NIH in the past, and limit appropriations for fiscal year 1987 accordingly.

Mr. NATCHER. Thank you very much Dr. Cohen.

WEDNESDAY, APRIL 30, 1986.

HEALTH ISSUES

WITNESS

GERTRUDE ENGEL

Mr. NATCHER. Our next witness is Ms. Engel. Ms. Engel, you come every morning real early. We will be pleased to put your written statement in the record in its entirety.

Ms. ENGEL. I need moral support from your committee to call on the rest of the Congressmen to please cosponsor the bill we talked about last year. That is for the use of Laetrile for cancer victims suffering from pain. There is no cure for cancer, and I hope that my 30 years of crying about it will have other people listen to me this time.

Now, I feel this way. Dr. Frank Young, I also saw him again and I keep seeing him at the various banquets and parties and he keeps assuring me that they are not doing anything to interfere with my work here in Washington and that we want a Federal law passed for the use of Laetrile. The greatest thing that affected me more than anything else, Mr. Natcher, was my appearance in Denver, Colorado because an attorney in the Justice Department—I don't know what is wrong with some of these people working for Government. Maybe they don't have enough to do—went to the Denver court to do away with Judge Luther Bohanan's decision which he gave me last December and that was that we have cancer relief of pain by using Laetrile.

Luther Bohanan, 83 years old, the most wonderful, sensitive individual I have ever met. I walked into his courtroom. He held my hand all the time we were talking and he agreed that we must do something for cancer victims suffering from pain.

He said, Ms. Engel, I don't know what to tell you. All these years you have kept the courts informed and you have done everything you possibly can.

We wouldn't have known any of this unless we heard from you. Lo and behold, in the Denver Court, would you believe it that an attorney from the Justice Department, Attorney Daniel, appeared in the appeals court, to ask that they do away with Judge Luther Bohanan's decision.

I couldn't believe it. I sat in that courtroom surprised that an attorney here in the Justice Department would annihilate what Judge Luther Bohanan was trying to do. And do you know everything he said was distorted.

And as I sat there, my sensitivity was so aroused, I got sick. I couldn't believe it.

The healthiest gal in America here getting ill because an attorney was distorting the facts. So naturally when we left Denver I called upon him only to find out that he came home with the flu.

I couldn't believe what had happened and I waited a week. His office said, call him back in a week, he might recover. He did. He recovered and I said, "Attorney Daniel, how could you possibly do what you did?" He said, "I know I distorted the facts," but I asked why? Have you ever lived with cancer victims? Do you know what they go through? I said I have. I said, "Why did you tell the court what you did?"

I said you didn't know anything about the research that I did in 1978 for the United States Supreme Court and he said no. I never heard about it.

I said, I tried to tell you a year ago that don't spoil anything for anybody. I have been in and out of all of these courts all these 17 years that I have been here. Don't do anything to make it so that we cannot have Laetrile for cancer victims and he said I never saw the report.

Well, I began to talk with the Lord, as I generally do every day, and got an answer, and the answer was send this research report to the Denver court.

Do you know, Mr. Chairman, I was so delighted they sent a letter back to me using my research. It was January the 28th of this year. The court has not given us a decision.

I hope they don't give us any at all, because they have this report now that I did for the United States Supreme Court whereby Justice Thurgood Marshall said why should we, sitting in a court of equity, decide the fate of Laetrile? He said it should be administrative and not judicial and then also the greatest thing that was said from Wade McCree, the former Solicitor General, who also said I am wondering about that myself.

The court came down with a nine to nothing decision that they are not going to make a decision on the use of Laetrile. Send it back to the lower court and believe it or not, Wade McCree agreed.

It went to a nine to nothing decision and everything turned out fine and I thought I was riding on the high seas. This is wonderful.

I am having success helping all the cancer victims. Believe it or not, the attorney filed a motion in the Denver court to do away with Judge Luther Bohanan's decision and I begged him not to.

I said, Judge Luther Bohanan is 83 years old. He is very sensitive. He was appointed by the late President John Kennedy to the bench in the Oklahoma court. Don't break his heart.

People die, I said, from broken hearts. Be sensitive to the fact that we do need Laetrile which is used by 1,000 doctors for relief of pain.

FREEDOM OF CHOICE

We have 23 States. In fact, your State okayed it, too. Kentucky okayed the use of Laetrile for cancer victims. However, what is happening now is coming slowly.

Cosponsorship is coming along too slowly. We are not asking for any funds. We just want moral support so we can get this bill passed this year and I am now awaiting a Senate companion bill.

But you know what I found, Mr. Chairman?

The use of the word "cancer" is far more frightening than the use of the word "war." People run away from it and they are not concentrating on the "Dear Colleague" letter Mr. Bill Goodling mailed. He begged for the Congressmen to support the bill, H.R. 1471 so we can get it passed this year.

But, unfortunately, no more than about a half a dozen Congressmen have cosponsored the bill and I need everybody's support to get this passed.

So, therefore, I am asking you, please, if you will do me a great big favor and let the committee contact the rest of the Congressmen as well as I do every single day and see if we can do something to get this bill passed to help cancer victims.

Because there isn't a day, and I tell you truthfully, that somebody is on the telephone crying from all over the country and begging me don't take my Laetrile away from me.

I said, please, I am only one person here in Washington. I am trying to do a job for you and I am doing my very best but I can't urge people to do things they don't care to do.

And they are begging because Laetrile gives them a sense of well-being. It has been proven non-toxic and clinically safe.

So that is what we need in the country today to help our cancer victims. We are not asking for any funds. We are just asking for moral support from everyone. I hope everybody here today writes to their Congressmen, tell them to support H.R. 1471 and I will be very happy.

Thank you very much, dear.

Mr. NATCHER. Ms. Engel, thank you very much. We appreciate your appearance. You have given us an excellent statement.

[The statement of Ms. Engel follows:]

LAETRILE UPDATE

Gertrude Engel
Health Advocate

The United States

HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON APPROPRIATIONS
Wednesday, April 30, 1986

Washington, D. C.

From one who is especially grateful for kindness.
Honorable Wm. H. Natcher, Kentucky Chairman

We thank you sincerely for the
privilege of admissible facts.

Mr. Chairman and the illustrious members of the Appropriations Committee, I am Gertrude Engel.

I represent the American Health Education Foundation and our more than 600,000 readers. Also, Mr. Victor Earl Irons, our 91-year-old "Mr. America for Health" from Cottonwood, California.

Please see attached pages 1 and 2.

Thank you.

-1-

The honor and privilege of appearing before you is appreciated and I will try to relate a quick update on the Laetrile issue.

The Honorable Wm. Goodling (R. Pa.) introduced H. R. 1471 allowing non-toxic Laetrile for relief of pain concerning cancer victims under the care of a physician. This was followed by a Dear Colleague letter.

Dr. Frank Young, Commissioner of the Food and Drug Administration tendered his approval to make this measure a Federal law.

The Honorable Judge Luther Bohanon, of the United States District Court for the Western District of Oklahoma, recently ruled to keep the affidavit system signed by a medical doctor intact.

The FDA issued a compassion plea for the use of Laetrile sometimes referred to as Amygdalin.

We are now awaiting a Senate companion bill.

In the meantime, January 28, 1986, in the United States Court of Appeals, Tenth Circuit, Denver, Colorado, a hearing was held before a three-judge-panel asking the Court to reverse Judge Luther Bohanon's decision. It was a sad scene - it aroused my sensitive nature hearing the distorted facts by Attorney Al J. Daniel, Jr. of the Justice Department.

A crowd including cancer patients assembled in the court room, Colorado is one of the 23 states that legalized Laetrile.

I will elaborate more in detail with your permission, please.

My 1978 research "Brief Amicus Curiae" for the U. S. Supreme Court was admitted in the Denver Court.

I remember Justice Thurgood Marshall's remark, "Should we sitting in a court of equity - decide the fate of Laetrile - it should be administrative and not a judicial decision." Wade McCree, Former Solicitor General said, "I am wondering about that myself." Court adjourned - 9 to 0 decision - remanded back to the lower court.

Many public utterances continue, wherever I travel, "Don't take my Laetrile away from me."

(more, please)

-2-

In the Phoenix Gazette - 1979 - documented testimonials from 76 people - Laetrile was overwhelmingly approved.

Robert Henderson, P.D., N.D., Henderson Metabolic Service in Baltimore, Maryland asserts that Laetrile reduces severity of pain. He believes that most Americans will be subjected to the same depressing cancer statistics for a long time. Therefore, he is very anxious for a Federal law, a betterment for cancer sufferers.

As of this date there is no decision from the Denver Court.

We are asking, please, to show a little love in your heart for freedom of choice.

Sometimes individual wisdom supersedes sceintific evidence.

Eternal blessings and God's constant care for your health, happiness and humor.

We love you.

Respectfully submitted,

Gertrude Engel

Gertrude Engel, C.D. N.S.

WEDNESDAY, APRIL 30, 1986.

ADAMHA

WITNESS

GUY LAMONICA, PRESIDENT, SACRAMENTO CHAPTER, AMERICANS FOR SUBSTANCE ABUSE PREVENTION

Mr. NATCHER. Our next witness is Mr. Guy Lamonica.

Mr. LAMONICA. Thank you for this opportunity to discuss funding priorities in the health care field on behalf of the Americans for Substance Abuse Prevention.

This is the first time our organization has appeared before your subcommittee. ASAP is a very young organization, but we boast of a membership of over 20,000.

I am here basically on the Administration's proposed fiscal year 1987 budget for the Alcohol, Drug Abuse and Mental Health Administration. We feel that it is going to be way too low, and we recommend the committee adopt the fiscal year 1987 funding proposals of the Coalition of Alcohol, Drug and Mental Health Organizations.

I am talking now as a parent of—my sons are both chemically dependent alcoholics, and my mother is an alcoholic, and she is recovering, and if this funding is not done, and if things are not found about what causes alcoholism and chemical abuse, we are going to have a lot of problems later on in life.

We feel to help offset this deficit, additional revenues can be raised by boosting the Federal excise tax on cigarettes to 32 cents per pack, and raising the excise tax on beer and wine.

Cigarette smoking and the abuse of alcohol are the major causes of illness and premature deaths in the United States today. We believe that those who smoke and drink excessively should help pay for the increase costs they generate for the medical system.

Thank you for this opportunity to present our views.

Mr. NATCHER. Thank you, Mr. Lamonica. We appreciate your appearance.

[The statement of Mr. Lamonica follows:]

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Pat Boone
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Joseph A. Califano, Jr.
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Hon. Herman E. Talmadge
Former U.S. Senator

Abigail Van Buren
Syndicated Columnist

Raymond Chavira
Commissioner, L.A. County
Commission on Alcoholism

Michael E. De Bakey, M.D.
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Ernest P. Noble, Ph.D., M.D.
Director, Alcohol Research, UCLA

Sue Rusche
Director, Families in Action

Jokichi Takamine, M.D.
Chairman, AMA Committee
on Alcoholism

Rev. David A. Works
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STATEMENT OF

GUY LAMONICA
PRESIDENT, SACRAMENTO CHAPTER

THE AMERICANS FOR SUBSTANCE ABUSE PREVENTION
400 FIRST STREET, NW, SUITE 712
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PRESENTED TO THE

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

CONCERNING

HEALTH CARE APPROPRIATIONS
FISCAL YEAR 1987

ON

APRIL 30, 1986

RECOMMENDATIONS:

A. Appropriate $385 million for National Institute on Mental Health (NIMH), $112 million for National Institute on Drug Abuse (NIDA) and $89 million for National Institute on Alcohol Abuse and Alcoholism (NIAAA), in accordance with the recommendations of the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) Appropriations Coalition.

B. Utilize additional research funds to develop research projects on patient placement, treatment outcome, barriers to treatment, DUI screening tests, treatment needs formulas, prevalence surveys, health hazards of "in" drugs, and technical assistance.

C. Appropriate $576 million for Alcohol, Drug Abuse and Mental Health (ADMH) block grant.

D. Restoration of resources for adequate funding of alcohol and drug abuse data collection and storage and continued funding for support of the National Clearinghouse for Alcohol Information.

E. Increase the federal excise tax on beer and wine to a rate equal to that of hard liquor, and increase the federal excise tax on cigarettes to 32 cents per pack, the level it would be at if indexed for inflation since 1951.

Mr. Chairman and members of the subcommittee:

Thank you for the opportunity to discuss funding priorities in the health care field on behalf of the Americans for Substance Abuse Prevention.

This is the first time our organization has appeared before your subcommittee. ASAP is a very young organization, but we boast of a membership of over 20,000.

ADAMHA PROGRAMS

ASAP congratulates ADAMHA for its leadership role in brain function and behavior research. The work on endorphins and their receptors has great relevance to chemical dependencies. Brain imaging technologies, supported by ADAMHA, are aiding in the study of many compulsive disorders as well as chemical dependency. Other areas well worthy of mention include ADAMHA's work in studying the inherited susceptibility to alcoholism, the toxic effects of alcohol, the incidence and prevalence of chemical dependencies and psychiatric disorders, adolescent alcoholism and now children of alcoholics, and the role of supportive environment in recovery from schizophrenic episodes.

For these reasons, we view the Administration's proposed fiscal year 1987 budget for ADAMHA as inadequate. In recognition of the deficit reduction commitment, while keeping in mind the need to continue a strong commitment to research, we recommend the committee adopt the FY'87 funding proposals of the coalition of alcohol, drug and mental health organizations.

Mr. Chairman, I would like to discuss the many areas of clinically related research which the Americans for Substance Abuse Prevention feel needs to be pursued:

- **Patient Placement** - Peer reviewers for Medicare, and employers daily decide that substantial numbers of chemically dependent or psychiatrically ill individuals cannot be admitted to certain programs because they are not "sick enough". Continued emphasis must be placed on research leading to the development of standardized patient placement systems to match chemically dependent or psychiatrically ill individuals with the appropriate level of care corresponding to the stage or severity of the disease diagnosed. People who are in the middle or late stages of a disease may need hospital care, while those in the early stages may only require outpatient treatment.

- **Treatment Outcome** - Research is particularly scarce in the areas of adolescent treatment outcomes and treatment of cocaine abusers. Recently, adolescent drug addiction and chemical dependency patients have swamped treatment and rehabilitation facilities. Many of our nation's young people are leading tragic lives because of chemical dependencies.

- **Barriers to Treatment** - Research is needed on why people with chemical dependency problems or psychiatric problems go without help for so long before receiving treatment, and the mechanisms for overcoming those barriers. For example, 85 percent of this nation's 14.7 million alcoholics and problem drinkers do not receive formal help for their disease. Of the

10-12 million children suffering from mental disorders, only 500,000 are receiving any kind of treatment through the mental health care system. The problems of alcohol and chemical dependencies, and mental disorders are still very much stigmatized by society and even the supposedly informed medical community. We encourage research efforts to eliminate these restrictions.

We recommend NIAAA and NIDA collaborate with the Department of Transportation on developing new tests for screening drunk drivers. Once tested, drunk drivers diagnosed as chemically dependent could be referred to legitimate treatment programs, rather than "education" classes.

- **Health Hazards of the In-Drugs** - Research is needed on some of the health hazards of such "in" drugs of adolescents as clover cigarettes, Liquid Paper, designer drugs, and hazardous substances that are inhaled or sniffed.

BLOCK GRANTS

The Administration's request for $490 million for alcohol, drug abuse and mental health block grants is at the same level as FY'86, but in real dollars it is at least a 10 percent cut from the FY'85 services. To maintain existing services and provide funds for programs for mentally disturbed children and chemically dependent women authorized in the ADM Block Grant Amendments, we urge adoption of a funding level of $576 million. While federal support for chemical dependency and community mental health services has declined during the past few years, the demand for services continues to increase.

NATIONAL DATA GATHERING

With the development of the block grant systems, states are no longer required to uniformly report data to NIAAA and NIDA. This lack of a comprehensive national data base, including all public and private programs, makes it difficult to know how many people are being treated, what their alcohol and drug problems are, where they are being treated and the like. We urge restoration of the National Drug and Alcoholism Treatment Utilization Survey, NIDA's Client Oriented Data Acquistion Process and other national data gathering studies.

NATIONAL CLEARINGHOUSE

ASAP understands that President Reagan's sequester order calls for a 23 percent reduction below appropriated levels in funding for the National Clearinghouse for Alcohol Information. We urge that funding levels for the clearinghouse be restored to appropriate levels. The clearinghouses are a vital link in disseminating the research findings to the health care and scientific communities, and they are a major resource accessible to anyone who seeks information about these deadly, but treatable diseases.

With deficit reduction the over-riding goal of Congress, we understand the Administration's attempt to reduce projected spending for Medicare and Medicaid by more than $5 billion in FY'87. However, we oppose the regulatory initiatives recommended to reduce projected spending. The proposed freeze on Prospective Payments to hospitals at FY'85 levels and on payments to PPS-exempt hospitals, reneges on a commitment made to hospitals to revise payment rates on an annual basis. Continued reductions will produce compromises in both accessibility and quality of care, especially that for alcohol and drug abuse treatment.

The Americans for Substance Abuse Prevention are aware of the current situation as it relates to payment for alcohol and drug abuse related to Medicare treatment under the DRG system. Without going into great detail, I would merely like to encourage Congress to closely follow the implementation of alcohol related DRG's and insure that adequate consideration is given those Medicare beneficiaries in the nation who are chemically dependent or substance abusers.

To help offset the deficit, we urge that additional revenues be raised by boosting the federal excise tax on cigarettes to 32 cents per pack and by raising the excise tax on beer and wine, as has been done with distilled spirits. Cigarette smoking and the abuse of alcohol are major causes of illness and premature death in the United States. A tenth of the drinking population comsumes half of the alcoholic beverages sold. We believe those who smoke and drink excessively should help pay for the increased cost that they generate for the medical system.

Mr Chairman, thank you for the opportunity to present our views. We very much look forward to a continued good relationship.

WEDNESDAY, APRIL 30, 1986.

ADAMHA, DEVELOPMENTAL DISABILITIES

WITNESS

PETER SAJEVIC, VICE PRESIDENT FOR GOVERNMENT CONCERNS, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

Mr. NATCHER. Mr. Peter Sajevic.

Mr. SAJEVIC. I am Peter Sajevic.

I am President and Executive Director of three private agencies in Minnesota which offer an array of community-based alternative services for people who are developmentally disabled, and home family services, supportive services and apartments, foster home and group home services certified as intermediate care facilities for the mentally retarded.

And I also serve as Vice President for Governmental Concerns for the National Association of Private Residential Facilities for the Mentally Retarded. That together provide residential services for more than 20,000 people with disabilities.

In the interest of time, I would like to submit our entire statement for the record, and will highlight our major concerns.

Many of the Federal programs under the jurisdiction of this subcommittee fund the delivery of residential and supportive services to people who are developmentally disabled, and are of vital interest to our national members.

My oral testimony today will concentrate on medicaid. Comments regarding the other programs are included in my written testimony.

NAPRFMR strongly opposes Administration efforts to cap its medicaid program. About 70 percent of all Federal support for community programs for people with mental retardation comes from medicaid. Most individuals served by NAPRFMR members are eligible for medicaid assistance due to income and disability status to cover cost of physician and hospital services, and for some residential and day services.

The emerging, not yet mature system of community-based services has demonstrated significant effectiveness, despite the increasing demands that severely strain existing resources.

In just 10 years, the availability of funding through certification as ICMFR under medicaid has spurred a vigorous development of community facilities, namely smaller programs of 50 people or fewer, and the demands placed on providers over the past few years have not been matched with equivalent resources.

As the number of people served have moved successfully through the program to self-independent living, providers have had to adapt their program to meet the needs of people with far more complex needs without commensurate resources.

For many providers, this is an exciting challenge and the changing Federal policies have caused many States to place caps or cuts on rates, which are exacting more restrictive administrative requirements.

Facilities have had to engage many nonprofessionals, lawyers, data processors, to meet new requirements and interpretations.

Federal look-behind surveys created new program emphasis and interpretations putting pressure on providers to do more for less. The recently available service alternative, home and community-based waiver under medicaid, would offer further viable and appropriate options for people with disabilities.

If the original design of the program to create flexibility could be restored—but the programs have worked. Mandatory education has made it possible for many of the generations to receive education, while staying in their own home.

Many now are seeking necessary and supportive services, however, beyond their school years, and many people have progressed to the ICFR system to less restrictive alternatives.

Deinstitutionalization efforts have tendered a promise of a life in the community. We have made promises that we could help them grow, and the promise is working.

We should be seeking more resources at this time to maintain and build upon our success, and we need to remember the promises that we have made and support those promises, and we also need to recognize that more people are in need of services today, and we can expect that need to grow.

At a minimum, we will ask you to support the CCDD recommendations as outlined in our written testimony.

Mr. NATCHER. Thank you, Mr. Sajevic.

[The statement of Mr. Sajevic follows:]

National Association of Private Residential Facilities
for the Mentally Retarded

6400H Seven Corners Place,
Falls Church, Virginia 22044

Area Code 703 / 536-3311

STATEMENT

RESPECTFULLY SUBMITTED TO THE
HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
OF THE HOUSE COMMITTEE ON APPROPRIATIONS
ON
FY 1987 APPROPRIATIONS
FOR MEDICAID, SUPPLEMENTAL SECURITY INCOME, SOCIAL SERVICES
AND THE COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING PROGRAM

Witness: Peter "Skip" Sajevic
NAPRFMR Vice President for Governmental Concerns
and
Executive Director of Nor Haven, Nekton & sur la rue
St. Paul, Minnesota

April 30, 1986

NAPRFMR WITNESS

Appearing in behalf of the National Association of Private Residential Facilities for the Mentally Retarded is Peter "Skip" Sajevic, NAPRFMR Vice President for Governmental Concerns and President/Executive Director of Nor Haven, Nekton and sur la rue, three agencies that together provide residential services to more than 500 people who are developmentally disabled. Many of the community-based living arrangements managed by Mr. Sajevic's agencies are intermediate care facilities for the mentally retarded. Others are funded through the SSI payments received by clients, Title XX Social Services funding, and a variety of other state and local resources.

DESCRIPTION OF THE ASSOCIATION

NAPRFMR represents almost 600 agencies and family care homes that provide residential services to more than 20,000 people with developmental disabilities in 48 states and the District of Columbia. About 40% of the Association's members serve 16 or fewer persons, one-third serve 17 to 50 people, 15% serve between 50 and 100 persons, and about 14% serve more than 100 individuals. Most members serve people in scattered, community living arrangements. Some have dozens of group homes and apartments, some are villages, others are private residential schools, and some are comprehensive, medically-related facilities. About 60% are nonprofit organizations, approximately 30% are proprietary corporations, and 10% are unincorporated family care providers. Together they offer a full range of residential services in a variety of settings, utilizing many different funding sources.

BACKGROUND

Many of the federal programs under the purview of this Subcommittee support the delivery of residential services to people who are developmentally disabled and are of interest to NAPRFMR members. For purposes of this testimony, we will focus on four which are of particular concern because they provide significant support for residential services. Three are programs authorized under the Social Security Act: Title XIX Medicaid, Title XVI Supplemental Security Income (SSI), and the Title XX Social Services Block Grant program. The fourth is the program of Comprehensive Services for Independent Living authorized by the Rehabilitation Act. Our emphasis today will be on the Medicaid program, but the interrelationship between Medicaid, the other programs cited, and yet additional avenues of support, makes it difficult to discuss one without mentioning the others.

As people with disabilities and low income, most of the individuals served by NAPRFMR members are eligible for Medicaid assistance, which covers the cost of physician and hospital services, and, for some, residential and day services. A major policy decision made by Congress in the early 1970s to correct the abuse and neglect found in many state institutions for people who are mentally retarded expanded the Medicaid program to provide comprehensive services this population through the certification of intermediate care facilities for the mentally retarded (ICFs/MR). For the first time, these persons and their families could hope for a brighter future. The ICF/MR program has demonstrated its effectiveness in facilities around the country — many operated by NAPRFMR members. As a result of these programs, people served are exceeding early expectations of their potential development, and as they become more self-dependent, many are able to move to semi-independent and independent living in the community that may be supported through other federal programs such as SSI, Title XX, and the Title XIX Waiver for Home and Community Based Services. Some engage in competitive employment and become tax payers.

According to the Health Care Financing Administration, as of January 1986, there were about 3,080 residential programs certified as ICFs/MR in the U.S., almost 70% of them operated by the private sector. More than one-third of the ICFs/MR (2,260) serve 4 to 16 persons. Based on earlier data, more than 140,000 people are receiving services in ICFs/MR today, about one-fourth of those served by the private sector. More than 100,000 additional people with developmental disabilities receive support for residential services from other federal state and private programs, 80% of whom are served by the private sector. The federal support for non-ICF/MR room and board comes primarily from SSI benefits provided to low-income people who are disabled, supplemented by programs such as those discussed above. The program of Comprehensive Services for Independent Living authorized by the Rehabilitation Act holds great potential for helping people move from more costly institutions to less restrictive settings when they become more self-dependent. Day programs that serve people in residential programs also receive some federal support. The Title XX Social Services Block Grant program has provided a major source of funding for day programs. Title XX is targeted to five basic goals which are primarily associated with self-support, self-sufficiency and non-institutionalization. Without day services, few residential programs are viable, and family care breaks down under the burden of 24-hour-a-day responsibility, leading eventually to institutionalization.

Unfortunately, the system leaves much to be desired. Waiting lists for our member facilities attest to the fact that thousands of people are awaiting community placements and services. Some of the individuals on waiting lists are in state institutions and nursing homes, but many live at home with their families. The Education of All Handicapped Children Act (P.L. 94-142) has succeeded in preventing the institutionalization of many children by supporting educational programs in public schools. Many of those served by 94-142 are now reaching the age of majority with few community day programs to go to. Families are often unable to cope with their adult children who must remain at home all day. Many parents are also growing older and are becoming infirm, so the demand for community residential and day placements is growing and will continue to grow in the coming decades. We must ask what would have happened in terms of human development and federal expenditure if these parents had sought institutional care for their children as was often the case prior to enactment of 94-142; and we must evaluate their prospects today.

As the result of cuts that have occurred in the Title XX Social Services Block Grant progam and other federal and state programs that support residential and day services (the latest as the result of the Gramm-Rudman-Hollings initiative), and with the constraints placed on the Medicaid Waiver for Home and Community Based Services, the ICF/MR program offers the primary avenue of hope for families who are seeking residential services.

MEDICAID

Under current law, aggregate Medicaid outlays for all purposes are expected to increase by $1.4 billion between FY 1986 and FY 1987. The Administration, however, is proposing legislative changes to limit program outlays by approximately that same amount in FY 1987. About $1.3 billion of that would come as a result of a statutory spending limitation, $260 million through administrative cost limitations, $30 million from the transfer of costs for refugee assistance, and $100 million from tighter enforcement of third party liability for medical expenses. This would be offset by a $300 million "hardship equalization fund" for states which, for reasons beyond their control, exceed the federal spending ceiling the Administration proposes to establish for FY 1987.

NAPRFMR opposes the Administration's plan to cap future federal Medicaid outlays. Such a cap would place a disproportionate share of the burden of reducing the federal deficit on millions of aging persons and thousands of people with developmental disabilities who represent the most vulnerable population in American society. Federal "look behind" surveys instituted over the past year and a half have resulted in new interpretations of federal ICF/MR ruleswhich in turn have led to an increase in the cost of services provided in ICF/MR facilities. ICF/MR providers are being required to increase staffing and professional services at a time they are being asked to reduce costs. These two mandates are obviously mutually exclusive. Although our members sometimes disagree with individual rulings of the federal survey teams when they require services not identified by the clients' interdisciplinary teams, we are totally supportive of the concept of surveys designed to assure that federal dollars are being spent for good, cost-effective programs. It is unconscionable for the federal government to be considering cutting funds for a program at the same time it is demanding services of the highest quality, particularly when funding for the only alternative funding sources available are also being frozen or cut.

The Medicaid Waiver for Home and Community Based Services has provided a viable alternative to the ICF/MR program for some of our clients who can live in the community if they receive support services of the type funded by the Waiver program. It can be a cost-effective method of serving people who would otherwise reside in institutions. Unfortunately, the regulations which implement the program make it difficult to serve as many people as are in need. NAPRFMR would like to see increased flexibility in the program so that more individuals can be diverted or removed from institutional settings.

NAPRFMR recommends that Administration efforts to cap the Medicaid program be rejected and that appropriations be established at the estimated expenditure level of $24.75 billion for client benefits, and total projected expenditures of $26.098 billion.

SUPPLEMENTAL SECURITY INCOME

As stated earlier, the Supplemental Security Income program (SSI) provides the major avenue of housing support for people with disabilities who meet income tests of eligibility. The Administration's FY 1987 budget projects a net increase of about $407 million in benefit payments over 1986, primarily because of a 3.7% cost-of-living increase expected in January 1987. and the addition of about 100,000 new SSI recipients. It also proposes an increase of $1 million (from $7 million to $8 million) for beneficiary services which fund vocational rehabilitation services, referral and monitoring. These services are designed to increase the employment potential of SSI recipients so that they can become self-supporting, and are a cost-effective use of federal funds.

The average SSI recipient who is disabled will receive an estimated $238 per month in FY 1987, including the January 1st COLA. If an individual has no other income, he or she can expect to receive a maximum of $348 in monthly SSI benefits, scarcely enough to survive. Despite its promises to protect the most vulnerable Americans, the Administration has proposed introducing legislation to improve "coordination among various cash benefit programs." This would result in reduced benefits to many people with disabilities who receive assistance from more than one federal program. As we have tried to explain, it is only with the careful coordination of several federal programs that people can be effectively served in the community to avoid more costly services or institutional placement.

NAPRFMR recommends that Congress reject the Administration's legislative proposals for the SSI program and appropriate $10.569 billion in FY 1987, the amount of expenditure estimated to be required under curent law.

TITLE XX SOCIAL SERVICES BLOCK GRANT

As indicated earlier in our testimony, many people with disabilities who live in the community are dependent on Title XX funding to pay for services which support them in their living environment and contribute to the cost of day programming.

The buying power of this program has been reduced by 40% since it was converted to a block grant in 1981. The conversion was accompanied by a 25% cut, inflation has taken its toll, appropriations were reduced for FY 1986, and Gramm-Rudman-Hollings has made still further cuts in the program. The President has proposed a funding level for Title XX in FY 1987 that is equal to the amount appropriated for FY 1986, before sequestration. At the same time, however, he is proposing that the Community Services Block Grant program be terminated in FY 1987, and that Title XX assume responsibility for services provided under the Community Services Block Grant. This would considerably increase the demand for Title XX dollars.

NAPRFMR recommends an appropriation of $3.3 billion for the Title XX Social Services Block Grant program in FY 1987. This would provide additional funds to move the program back toward pre-1981 levels. The Association also opposes termination of the Community Services Block Grant program, which would significantly increase the responsibility of the Social Services Block Grant without the provision of additional funds to cover the increased demand.

COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

Part A of Title II of the Rehabilitation Act establishes a nationwide program of Comprehensive Services for Independent Living to assist people "whose disabilities are so severe that they do not presently have the potential for employment but may benefit from . . . services which may enable them to live and function more independently." When the program was enacted in 1978, a funding level of $200 million was authorized, but the program did not receive any appropriations until FY 1985, when $5 million was approved for start up costs. That amount was increased to $11 million in FY 1985, but this too was viewed as seed money provided to "assist the state[s] . . . to establish a sound basis for future additional funding of this activity."

The Administration has proposed that no funds be appropriated for this program in FY 1987. Without them, individuals with severe disabilities will be denied the opportunity to become more self-reliant and thus will be more dependent upon other more costly federal, state and local maintenance and entitlement programs. Our Association would like to see the appropriation of sufficient funds for the establishment of a real national service delivery network under the Part A program of Comprehensive Services for Independent Living.

NAPRFM recommends that $30 million be appropriated for the Comprehensive Services for Independent Living Program in FY 1987.

CONCLUSION

NAPRFMR supports the appropriation recommendations previously provided to the members of this Subcommittee in the CCDD Analysis of the President's FY 1987 Budget Proposals and Recommended Appropriation Levels Relating to Programs for People with Developmental Disabilities, and urges careful consideration of that entire document.

WEDNESDAY, APRIL 30, 1986.

RAILROAD RETIREMENT BOARD

WITNESSES

OLE M. BERGE, RAILWAY LABOR EXECUTIVES' ASSOCIATION
WILLIAM G. MAHONEY
JAMES SNYDER

Mr. NATCHER. Next we will hear from Mr. Berge and Mr. Mahoney. Come around. Mr. Snyder.

Mr. BERGE. Thank you, Mr. Chairman.

My name is Ole M. Berge. I am President of the Brotherhood of Maintenance of Way Employees, and Chairman of the Railway Labor Executives' Association, or RLEA, as well as Chairman of the RLEA's Committee on Railroad Retirement. I am accompanied by Mr. James R. Snyder, Chairman of the RLEA Legislative Committee, and William G. Mahoney, RLEA Counsel.

Mr. Chairman, the last several months have been difficult ones for railroad retirees. We have been hit by a three-way attack that is not over.

First, the Gramm-Rudman-Hollings Act made severe and unwarranted cuts in railroad retirement benefits. It eliminated our Tier 2 COLA. It reduced dual payments for over 300,000 beneficiaries by 7.7 percent.

Next, the Budget Reconciliation Act substantially increased income tax for many railroad retirees and made an already complicated system even more complex and difficult to understand and administer.

Finally, the President submitted his budget for fiscal year 1987. That budget would eliminate our next Tier 2 COLA entirely. It would reduce our future COLAs. It calls for brutal reductions in dual benefits.

It would require reductions in disability benefits for any of our employees who recover under the Federal Employers' Liability Act for injuries suffered on their jobs. It threatens again to privatize our retirement system and transfer our unemployment program to the Federal-State system.

Mr. Chairman, these actions are not justified. They are, indeed, grossly unfair to the retired and disabled railroad workers of this country.

Mr. Chairman, our retirees will not understand the changes made in the Budget Reconciliation Act. Almost 500,000 Tier 1 benefits will have to be recomputed. This will be just for tax purposes.

Will the Railroad Retirement Board staff be able to recompute 500,000 Tier 1 amounts by January 1, 1987 and keep track of 500,000 Tier 1 amounts under two different laws?

Under one law for tax purposes and under the other so that they can make correct monthly annuity payments? Will they be able to do this and still maintain service to our constituents? We do not think so.

Why is all this being done to a system financed by a trust fund which cannot be used for any other purpose? The answer is that all these unfair actions are being undertaken to help offset, on paper, deficits elsewhere in the Federal budget. It is being done for no other reason.

Mr. Chairman, I am aware that this is an appropriations committee, not an authorization committee. But this committee has always been sensitive and compassionate toward the retirees of our great Nation.

It has always been understanding and helpful to railroad retirees. For that reason, I would call to your attention two matters which are within the jurisdiction of this committee.

First, in view of the severe 7.7 percent reduction in dual benefits this year, I ask that the committee consider nothing less than full funding of the dual benefit program for fiscal year 1987. Full funding would require $380,000,000. This is $12,000,000 less than this year's appropriation

Mr. Chairman, we thought this issue was settled in 1974. We thought it was settled in 1981. And yet, dual benefits were severely cut in April of this year. Anything less than full funding means again reducing benefits from levels retirees have been receiving, and have budgeted for, and which had been promised to them.

Second, Mr. Chairman, we are concerned that the implementation of the tax increase provisions of the Reconciliation Act will drain Railroad Retirement Board personnel from other functions. We are told that this tax change will be the most complicated administrative undertaking in the history of the Board.

Nevertheless, the Administration's budget calls for a reduction in the number of people available to administer our retirement program. Mr. Chairman, reductions in personnel in the Railroad Retirement Board at a time when they have this burdensome new task to perform would be disastrous.

Service to our retirees surely would suffer. At the same time, we are asked to spend $1,167,000 from our trust fund to hire 25 people to man the recently established office of Inspector General. We respectfully submit this makes no sense.

It would indeed be unfair if railroad retirees suffered a loss of service because of a reduction in personnel that we fund ourselves at the same time the Board is trying to hire 25 people to implement changes in the law creating the Office of Inspector General which we did not want and do not need.

Mr. Chairman, this committee has always been sensitive and fair to the welfare of railroad retirees. It has always shown compassion. Railroad retirees are grateful for the efforts of this committee. We ask again for your understanding and help on these two important issues.

Thank you.

Mr. NATCHER. Thank you, Mr. Berge.

[The statement of Mr. Berge follows:]

BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND
HUMAN SERVICES AND EDUCATION
OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 30, 1986

Mr. Chairman:

My name is Ole M. Berge. I am President of the Brotherhood of Maintenance of Way Employes and Chairman of the Railway Labor Executives' Association or RLEA as well as Chairman of the RLEA's Committee on Railroad Retirement.

The Railway Labor Executives' Association is an unincorporated association with which are affiliated the chief executive officers of all of the standard national and international railway labor unions in the United States. The organizations whose chief executive officers are members of the RLEA are listed below:

American Railway & Airway Supervisors Association, Division of BRAC
American Train Dispatchers Association
Brotherhood of Locomotive Engineers
Brotherhood of Maintenance of Way Employes
Brotherhood of Railroad Signalmen
Brotherhood Railway Carmen of the United States and Canada
Brotherhood of Railway, Airline & Steamship Clerks
Hotel & Restaurant Employees and Bartenders International Union
International Association of Machinists & Aerospace Workers
International Brotherhood of Boilermakers & Blacksmiths
International Brotherhood of Electrical Workers
International Brotherhood of Firemen & Oilers
International Longshoremen's Association

National Marine Engineers' Beneficial Association
Sheet Metal Workers' International Association
Seafarers International Union of North America
Transport Workers Union of America
United Transportation Union

Mr. Chairman, the last several months have been difficult ones for railroad retirees. We have been hit by a 3-way attack that is not over.

First, the Gramm-Rudman-Hollings Act made severe and unwarranted cuts in railroad retirement benefits. It eliminated our Tier 2 Cola. It reduced dual benefit payments for over 300,000 dual beneficiaries by 7.7%.

Next, the Budget Reconciliation Act substantially increased income tax for many railroad retirees and made an already complicated system even more complex and difficult to understand and administer.

Finally, the President submitted his budget for fiscal year 1987. That budget would eliminate our next Tier 2 Cola entirely. It would reduce all our future Cola's. It calls for brutal reductions in dual benefits. It would require reductions in disability benefits for any of our employees who recover under the Federal Employers' Liability Act for injuries suffered on their jobs. It threatens again to privatize our retirement system and transfer our unemployment program to the federal/state system.

Mr. Chairman, these actions are not justified. They are, indeed, grossly unfair to the retired and disabled railroad workers of this Country. In 1983, railroad labor and management joined in supporting one of the toughest and most agonizing pieces of legislation with which I have ever been involved. That was the Solvency Act of 1983. Its purpose was to save the Railroad Retirement Program which was then in financial trouble. Because of the sacrifices shared in that Act by rail labor, management and railroad retirees, the Act worked.

Rail labor and management agreed to have their already high employment taxes raised substantially. Employees now pay 4.25% over the social security rate. Employers now pay 14.75% over the social security rate. It should be emphasized that these rates are in addition to the social security level tax which both employees and carriers also pay.

Retirees made heavy contributions to the Solvency Act through dramatic benefit reductions, Cola offsets, and taxation of their Tier 2 benefits.

The Solvency Act saved the railroad retirement program. The latest report of the Board's actuary indicates that the system is sound for the rest of this century even under low employment assumptions.

As a result of the sacrifices made in the Solvency Act, the railroad retirement system can pay in full its obligations to railroad retirees. But this is only as a result of the sacrifices of labor, management, and retirees in accepting higher payroll taxes, benefit reductions, Cola offsets, and income tax on their annuities.

Despite the Solvency Act, Mr. Chairman, Gramm-Rudman eliminated our 1986 Tier 2 Cola. It did this even though our account is solvent; even though the savings stay in the account and cannot be used for any other purpose. And it did this despite the fact that the retirees' have already been deprived of their 1984 and 1985 Tier 2 Cola's.

Gramm-Rudman reduced dual benefits even though dual beneficiaries have already suffered unprecedented benefit reductions. Dual beneficiaries were cut in the 1974 Act, and in the 1981 Amendments. They were cut in 1982, and they were just cut again in April. And, as railroad retirees, they also experienced all the other recent benefit reductions.

On top of Gramm-Rudman, the Budget Reconciliation Act came along and raised income tax for many retirees. The hardest hit will be disabled retirees who no longer can work in their regular railroad occupations. Early retirees and widows will also be affected by the tax change.

It is worth noting that the Tax Amendment was pushed through while the administration was saying it would stand for no tax increase. And it was done while the Congress was working on a more appropriate vehicle if such a change was to be made. That vehicle is the tax reform legislation which could have balanced any tax increase on retirees with offsetting adjustments elsewhere.

Mr. Chairman, our retirees will not understand the changes made in the Budget Reconciliation Act. Almost 500,000 Tier 1 benefits will have to be recomputed. This will be just for tax purposes. Will retirees know the difference between an income tax Tier 1 and their actual Tier 1? Will the Railroad Retirement Board be able to recompute 500,000 Tier 1 amounts by January 1, 1987?

Will the Board staff be able to do this, and keep track of 500,000 Tier 1 amounts under two different laws? Under one law for tax purposes and under the other so that they can make correct monthly annuity payments? Will it be able to do this and still maintain service to our constituents? We do not think so.

Notwithstanding the sacrifices in the Solvency Act, and Gramm-Rudman, and the Budget Reconciliation Act, the President's budget threatens even more harsh treatment for rail retirees.

Why is all this being done to a system financed by a Trust Fund which cannot be used for any other purpose? The answer is that all these unfair actions are being undertaken to help offset, on paper, deficits elsewhere in the federal budget. It is being done for no other reason.

Mr. Chairman, I am aware that this is an appropriations committee, not an authorization committee. But this Committee has always been sensitive and compassionate toward the retirees of our great Nation. It has always been understanding and helpful to railroad retirees. For that reason, I would call to your attention two matters which are within the jurisdiction of this Committee.

First, in view of the severe 7.7% reduction in dual benefits this year, I ask that the Committee consider nothing less than full funding of the dual benefit program for fiscal year 1987. Full funding would require $380,000,000. This is $12,000,000 less than this year's appropriation.

Mr. Chairman, we thought this issue was settled in 1974. We thought it was settled in 1981. And yet, dual benefits were severely cut in April. Anything less than full funding means more reductions in the annuities of individuals who have already been cut many times. It means again reducing benefits from levels retirees have been receiving, and have budgeted for, and which had been promised to them.

Second, Mr. Chairman, we are concerned that the implementation of the tax increase provisions of the Reconciliation Act will drain Railroad Retirement Board personnel from other functions. We are told that this tax change will be the most complicated administrative undertaking in the history of the Board.

Nevertheless, the administration's budget calls for a reduction in the number of people available to administer our retirement program. Mr. Chairman, reductions in personnel in the Railroad Retirement Board at a time when they have this burdensome new task to perform would be disasterous. Service to our retirees surely would suffer. At the same time we are asked to spend $1,167,000 from our Trust Fund to hire 25 people to man the recently established office of Inspector General. We respectfully submit this makes no sense.

Mr. Chairman, as you know, the administrative expenses for railroad retirement are paid from the railroad account. These expenses include the cost of personnel. The railroad retirement account, of course, comes from the taxes paid by rail employees and employers.

It should be noted that rail labor and management, which ultimately finance personnel costs, are not asking for a reduction in personnel.

It would indeed be unfair if railroad retirees suffered a loss of service because of a reduction in personnel that we fund ourselves at the same time the Board is trying to implement changes in the law creating the office of Inspector General which we did not want and do not need.

Given the enormous task of restructuring Tier 1 benefits for income tax purposes, and informing annuitants of this change and explaining it to them, more personnel is needed, not less.

Accordingly, we would respectfully request that this Committee give serious consideration to granting the Railroad Retirement Board an increase in its personnel level from the current 1578 to 1623, the number requested by the Board in its 1987 budget submission.

Mr. Chairman, this Committee has always been sensitive and fair to the welfare of railroad retirees. It has always shown compassion. Railroad retirees are grateful for the efforts of this Committee. We ask again for your understanding and help on these two important issues.

Thank you.

ORAL STATEMENT OF A. M. RIPP

APRIL 30, 1986

MY NAME IS ANDREW M. RIPP. I AM VICE PRESIDENT OF THE INTERNATIONAL BROTHERHOOD OF ELECTRICAL WORKERS AND A MEMBER OF THE RAILWAY LABOR EXECUTIVES' ASSOCIATION. I APPEAR BEFORE YOU AS CHAIRMAN OF THE ASSOCIATION'S COMMITTEE ON THE RAILWAY LABOR ACT.

WE URGENTLY REQUEST YOU NOT TO PERMIT A REDUCTION IN THE $6.54 MILLION APPROPRATION TO THE NATIONAL MEDIATION BOARD BECAUSE THE NMB, AS THE ADMINISTRATOR OF THE NATIONAL RAILROAD ADJUSTMENT BOARD AND THE SUPPLEMENTAL BOARDS CREATED BY THE 1966 AMENDMENTS TO THE RAILWAY LABOR ACT, WILL PLACE THE ENTIRE BURDEN OF THAT REDUCTION UPON THE SERVICES RENDERED EMPLOYEES TO RESOLVE THEIR GRIEVANCES UNDER THE ACT.

AT THE PRESENT TIME, SOME 30,000 CASES ARE PENDING INVOLVING EMPLOYEE GRIEVANCES. IN 1986, SOME $2.12 MILLION IS TO BE PAID REFEREES. WE ARE TOLD THAT $209,000 OF THE $218,000 GRAMM-RUDMAN

REDUCTION IS TO COME OUT OF THE MONIES BUDGETED FOR REFEREES. THE PURPOSE OF THE NRAB IS TO SERVE THE RAILROAD EMPLOYEES OF THIS NATION NOT THE BOARD'S ADMINISTRATOR OR ITS OTHER FULL-TIME EMPLOYEES. THERE IS NO REASON TO CUT BY SOME 10% THE VERY PURPOSE OF THE BOARD'S EXISTENCE WHILE CUTTING THE NMB/NRAB HOUSEKEEPING FUNCTIONS BY 1%.

THE CONGRESS HAS MADE A NUMBER OF SIGNIFICANT CHANGES IN THE RAILWAY LABOR ACT SINCE THE NRAB WAS CREATED AND BEGAN FUNCTIONING IN 1934. AT NO TIME HAS THE CONGRESS INDICATED THAT THE SERVICES PROVIDED BY THE BOARD SHOULD BE CURTAILED.

THE SCHEME OF THE RAILWAY LABOR ACT IS VERY DIFFERENT FROM THAT OF THE LABOR MANAGEMENT RELATIONS ACT BECAUSE ONE OF THE FORMER ACTS MAJOR PURPOSES WAS, AND IS, TO REDUCE THE OCCASION FOR STRIKES IN THE RAILROAD INDUSTRY TO AN ABSOLUTE MINIMUM. IT HAS BEEN PRAISED BY LEGISLATORS, THE COURTS AND LEGAL SCHOLARS ALIKE FOR THE MANNER IN WHICH IT HAS ACCOMPLISHED THAT OBJECTIVE - AN OBJECTIVE WHICH NMB/OMB WOULD NOW DESTROY BY ARBITRARILY AND EFFECTIVELY PHASING OUT BOTH THE NRAB AND THE SUPPLEMENTAL BOARDS.

IT IS THE VIEW OF RAIL LABOR THAT IF NMB/OMB ACHIEVE THEIR GOAL, THE BASIS FOR RAIL LABOR'S HAVING GIVEN UP ITS RIGHT TO STRIKE OVER GRIEVANCES WILL HAVE BEEN REMOVED. THERE WILL BE IN LAW NO COMPULSORY ARBITRATION REQUIREMENT ON MANAGEMENT OR LABOR IN THE RAILROAD INDUSTRY BECAUSE THERE WILL BE NO PLACE WHERE THE PARTIES WILL BE ABLE EFFECTIVELY TO SUBMIT THEIR GRIEVANCES TO BE ARBITRATED. SINCE THE CHICAGO RIVER DECISION HELD THAT RAIL UNIONS CANNOT STRIKE BECAUSE OF THE EXISTENCE OF AN ARBITRATION BOARD TO WHICH THEY MUST SUBMIT THEIR "MINOR" DISPUTES, IT WOULD SEEM QUITE CLEAR THAT THE EFFECTIVE ABSENCE OF SUCH A BOARD OR ITS ABILITY TO PERFORM THE SERVICES FOR WHICH IT WAS DESIGNED AND CREATED, ENABLES THE RAIL UNIONS TO STRIKE OVER SUCH DISPUTES JUST AS DO UNIONS IN OTHER INDUSTRIES. THE NMB/OMB GOAL, IF ACHIEVED, WILL PLUNGE RAIL TRANSPORT INTO CHAOS.

A TOTAL APPROPRIATION OF $2,624,000 IS NECESSARY TO ENABLE THE NRAB (TOGETHER WITH THE SPECIAL BOARDS) TO CARRY OUT ITS STATUTORY FUNCTIONS AND THE OBJECTIVES OF THE LABOR PEACE SO CAREFULLY DESIGNED

INTO THE RAILWAY LABOR ACT. WE URGENTLY REQUEST THAT APPROPRIATION BE MADE FOR THE USE OF THE NRAB WITH A CLEAR DIRECTIVE FROM THIS COMMITTEE THAT AT LEAST $2.12 MILLION OF THAT AMOUNT BE USED FOR THE EMPLOYMENT OF REFEREES. THE NRAB MUST BE ALLOWED TO DO THE JOB IT WAS CREATED TO DO IF CONGRESS IS TO KEEP THE BARGAIN IT MADE WITH RAIL LABOR IN 1934.

THANK YOU.

Mr. **Natcher**. Mr. Ripp, we will be pleased to hear from you.

Mr. **Mahoney**. Thank you, Mr. Chairman.

I can understand the confusion. My name is Mr. Mahoney. Mr. Ripp couldn't make it out of Chicago today. He has a formal statement and an oral statement, which I asked that I read; but in the interest of time, I would ask that that be also placed in the record.

Mr. **Natcher**. Thank you, Mr. Mahoney, we will be delighted to do that.

Mr. **Mahoney**. Thank you, sir.

Mr. **Natcher**. Mr. Snyder?

Mr. **Snyder**. It is always a pleasure to come before this committee, and on both sides of the aisle here, and the staff.

Over the years, as Mr. Berge stipulated here, you have shown great compassion, great understanding for the railroad retirement problems; and at this time, it would be an ambush to deliver too much.

We appreciate all you have already done for us, and any consideration on these proposals, we appreciate very much. Thank you very much.

Mr. **Natcher**. Mr. Snyder, thank you very much.

Gentlemen, we appreciate your appearance. Rest assured that every consideration will be given to your request. Thank you, gentlemen.

Wednesday, April 30, 1986.

VETERANS PROGRAMS IN THE DEPARTMENT OF LABOR

WITNESSES

PAUL S. EGAN, DIRECTOR, NATIONAL LEGISLATIVE COMMISSION, THE AMERICAN LEGION

DENNIS K. RHOADES, DIRECTOR, NATIONAL ECONOMICS COMMISSION

Mr. **Natcher**. Our next witness is Mr. Egan. Come around, Mr. Egan. You have with you Mr. Rhoades, is that correct?

Mr. **Egan**. Yes, Mr. Chairman. Dennis will summarize our statement for us.

Mr. **Natcher**. All right, go right ahead.

Mr. **Rhoades**. I am the Director of Economics for the American Legion. We appreciate the opportunity to be here today. We realize it is getting late in the afternoon, and we will attempt to be brief in summarizing our statement.

I am sure the committee is well aware of the importance of the Department of Labor to the veterans' service system. Most of the employment services provided for veterans are provided through the Department of Labor and now through the VA, and very often, in the legislative process, can get shunted aside simply because they are not VA identified, and yet the services provided for the general population by the Labor Department, such as the JTPA, employment service, are very much a part of the veterans' employment system established by Congress, so that any changes in these programs likewise affect veterans applying for services.

Having said all of that, I think we are pleased to report to you, Mr. Chairman, that we find the Labor Department budget for veterans in 1987, submitted by the Administration, generally acceptable, in light of the Gramm-Rudman-Hollings deficit reduction efforts.

We do caution, however, that the budget for the employment service is probably, in our view, at rock bottom, and any further cuts in the employment service in fiscal year 1988 or indeed, this year, could result in a substantial reduction in services to veterans that must rely on that system.

We have two problems with the DOL budget. The first problem is the funding for the local veterans' employment representatives. This is a program that has been around since the original GI Bill in 1944, which has a veterans' employment representative in each job service office.

Currently, there are about 1450 of these representatives. The Administration is proposing to cut this program by about 225 individuals. We believe this is going to have an adverse impact on the services veterans can obtain through the job service, and we also think that the cut, which was purportedly based on changes in criteria for assignment of these individuals, is probably most explained in the Labor Department budget, which said that the amount of money for the veterans' employment representative program was determined by the number of positions—rather, was determined by dividing the amount available by the average cost per staff-year.

The American Legion would like to see the current number of VERs maintained in the employment service in 1987.

Our second problem concerns the JTPA, Title IV–C. Even there apparently has been a major increase in the funding, it was about $8,666,000 for fiscal year 1986, and will be about $10,333,000 for fiscal year 1987.

We think that since that is all the funding available to the veterans in need of help out of a $3,500,000,000 program, that that needs some reexamination.

While we are talking about IV–C, Mr. Chairman, we would like to take this opportunity to express how pleased we were with your opposition to the Labor Department's recision of about $600,000 out of the 1986 budget for the program.

We assure you that money will be spent well.

In conclusion, as you are probably aware, the House has identified $35,000,000, and this is not under the subcommittee's purview as such, in the Veterans' Administration's minor construction fund, and wants to move it for use in the Veterans' Job Training Act.

We understand there is a lot of reluctance in the Senate to go along with that, and we urge the committee to stand firm on that position as you go to conference.

That concludes my statement.

[The statement of Mr. Egan follows:]

Statement of

The American Legion

1608 K STREET, N. W.
WASHINGTON, D. C. 20006

by

PAUL S. EGAN, DEPUTY DIRECTOR
NATIONAL LEGISLATIVE COMMISSION
THE AMERICAN LEGION

and

DENNIS K. RHOADES, DIRECTOR
NATIONAL ECONOMICS COMMISSION
THE AMERICAN LEGION

before the

LABOR, HEALTH, AND HUMAN SERVICES SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

on

FY '87 LABOR APPROPRIATIONS FOR VETERANS

APRIL 30, 1986

TESTIMONY OF
DENNIS K. RHOADES
DIRECTOR FOR ECONOMICS
THE AMERICAN LEGION

before the

LABOR, HEALTH, AND HUMAN SERVICES SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

APRIL 30, 1986

Mr. Chairman, The American Legion appreciates this opportunity to appear before the subcommittee today to discuss the funding for veterans employment programs within the Department of Labor. Although they are often not accorded as high a profile as other veterans services, job services are no less vital to the readjustment and restoration of veterans to civilian life. Moreover, employment and training opportunities are an integral part of the social contract our Nation has made with its former soldiers, and deserve the same attention and care which the Congress has accorded to other services, such as veterans health care, home loans, rehabilitation, and compensation for service-connected disabilities.

Unfortunately, this has very often not been the case in recent years. For most of the public, including veterans, services for veterans have been almost exclusively identified with the Veterans Administration. While the VA provides many services to veterans, two major (and important) service areas are not within its purview: employment and small business assistance. Except for disabled veterans vocational rehabilitation, and a moribund on-the-job training program, job and job training assistance for our veterans has been vested by Congress with the Labor Department, which is why we are appearing before this subcommittee today.

Parenthetically, I think it is worth observing that small business generation is an important part of the job placement equation. In that regard, Mr. Chairman, The American Legion would like to express publicly our support for continuation of the Small Business Administration, which has been the target of the Administration for the last several years. As you are aware, nearly 80 percent of all new jobs in the United States are being created by small business. Fully 27 percent of all SBA business loan guarantees have been made to veterans this last year. Not only does this impact the ability of an entire generation of Vietnam-era veterans to realize the American dream of private entrepreneurship, but also generates thousands of new employment opportunities for their fellow veterans.

In contrast with the imminent peril in which small business assistance now finds itself, Mr. Chairman, we are pleased to report to you today the Administration's proposed budget for the basic veterans program functions at the Department of Labor, with two exceptions, appears adequate for the Department to carry out its legislatively mandated responsibilities. We congratulate Secretary Brock and Assistant Secretary Don Shasteen for their commitment to veterans and wise management of program funds. In our estimation, greater funding should be provided to State Employment Security Agencies so they may function as an effective labor exchange. In the context of the present deficit problem, however, it appears as if the proposed FY 1987 budget provides sufficient funding to maintain the integrity of the Job Service. We note this with the caution, however, that any future adverse changes in funding for the public employment service will have a profound effect upon the Federal government's efforts to assist jobless veterans. State Employment Agencies are the keystone of veterans employment programs, and it is impossible to alter the former without affecting the latter.

We are particularly gratified to note that funding for the Job Training Partnership Act (JTPA), Title IV(c) will be increased under this proposed budget. In that regard, Mr. Chairman, we would like to point out that the Administration, in February of this year, attempted to impose a $576,000 rescission on the 1986 budget for the program, in addition to the 4.3 percent, or $416,000 rescission, required by Gramm-Rudman. Early last month, we wrote the subcommittee, advising against approving that new rescission, since the Administration offered no justification for the reduction. We want to express our appreciation, Mr. Chairman, for your position in opposition to this rescission, as expressed in your letter of April 7, 1986 to our Legislative Director E. Philip Riggin. In addition, although a $1.8 million increase in Title IV(c) funding in FY 87 is a positive step for veterans, it pales into insignificance when compared to JTPA's $3.4 billion in resources. We urge the subcommittee to provice an additional $50 million for Title IV(c).

The second proposal in the Administration's budget which the Legion finds unacceptable is the line item for Local Veterans Employment Representatives (LVERs). The FY 1987 budget proposes to reduce the number of funded positions by 275 from its FY 1985 level, and 125 positions under the FY 1986 Gramm-Rudman level. Although the Administration claims that this reduction is owing to a change in regulations which eliminates consideration of local office veteran population in determining whether there is a need for a full-time LVER and, instead, depends solely on local Job Service office activity, the reasoning in the Administration's budget submission is perhaps more enlightening: "The number of LVERS," the document says, "is determined by the amount available (emphasis added), divided by the FY 1987 average cost per staff year." What this is telling us, Mr. Chairman, is that, in this top-down process, need for services was nowhere considered in the Administration's budget, despite the fact that the law (38 USC 2004) is very explicit about need as the single determining factor in the fulltime status of these positions. Even if one were to accept the ostensible reason for these reductions, the single criterion of local office activity is, by its very nature, regressive, and will discourage many local office managers experiencing staff cuts in other areas to permit Disabled Veterans Outreach Program (DVOP) and LVER staff to conduct the outreach required by law. The regulations reward offices with minimal contact with the veterans community by allowing them to assign LVERs to other, nonveteran duties. We urge the subcommittee to reject this proposal for an arbitrary and capricious reduction, and to insist that the Department of Labor rely on need as the only criterion for these positions and the requisite funding involved.

Althoughnot under the purview of this subcommittee, of principal concern to The American Legion is the fate of the Veterans Job Training Act (VJTA) which the Congress passed late last year. We note that the VA's budget for FY 1987, as well as for a FY 1986 supplement, does not include the $65 million authorized under the new legislation for the conduct of the program. This comes as no surprise, since 1987 will mark the fourth successive fiscal year in which OMB has attempted to bury this program through lack of funding. We have spoken on a mumber of occasions of the chronic structural unemployment problems experienced by Vietnam era veterans, and the same conditions exist today as those which prompted the Congress to pass this legislation, in the face of Gramm-Rudman, four months ago. The Appropriations Committee in the House has approved the reprogramming of $35 million within the VA to operate VJTA for the remainder of FY 1986. Should this proposal have no Senate counterpart by the time the measure goes to Conference, we ask that the Committee stand firm. With less than $17 million remaining in carry-over funds for VJTA, we need swift and resolute action to guarantee the uninterrupted conduct of the program.

Mr. Chairman, on behalf of the nearly three million members of The American Legion, may I say that we are pleased to have the chance to share with you our views on the matters under consideration today. We would be happy to answer any questions.

WEDNESDAY, APRIL 30, 1986.

JOB CORPS

WITNESS

ROBERT ROBINSON, DIRECTOR, WESTOVER JOB CORPS CENTER

Mr. NATCHER. The next witness is Dr. Robert Robinson.

Mr. Conte, I yield to you.

Mr. CONTE. Thank you, Mr. Chairman.

I want to add my personal welcome to Mr. Robinson. He runs, Mr. Chairman, one of the best Job Corps centers in the country up there in Westover, just across the Holyoke line, and I am sure he will give us some good advice. He happens to be a good friend of mine.

Mr. ROBINSON. Mr. Chairman, I am Robert Robinson, Center Director of the Westover Job Corps Center in Chicopee, Massachusetts. My employer, the RCA Service Company, has operated Job Corps centers since 1965.

I am honored to present this statement to you today on behalf of many business, labor and volunteer organizations associated with Job Corps. An up-to-date listing of the strong supporters of Job Corps is included in my statement.

Mr. Chairman, you and my distinguished Congressman from Massachusetts, Mr. Conte, recognize how far Job Corps has come in over 20 years of operation. Through experimentation and innovation, Job Corps has been able to capitalize on its initial mistakes.

Our early failures taught us that conventional approaches to education and training did not succeed with the Job Corps population. And so, we developed and perfected a residential, open-entry, open-exit, vocational and basic education model that is effective.

Job Corps now enjoys well-deserved respect from the American public and the Congress. It is sadly ironic that today, Job Corps must fight harder than ever to justify its continuation and, most immediately, to avert center closings this summer.

On this note, I would like to highlight the two major themes of my testimony:

One, Job Corps needs the leadership of this committee to overturn the Administration's plans to close two to eight Job Corps Centers starting July 1, 1986.

Two, Job Corps needs a current services funding level of $665,600,000 in fiscal year 1987.

With respect to center closings, there are grave concerns. Purportedly, the Administration intends to close the "high-cost, low-performing" centers as a management tool to increase the program's overall unit cost efficiency. This rationale is flawed.

First, unacceptably high cost centers or low Job Corps center performance should be corrected through proper program administration, not through center terminations.

Second, center closings go beyond the scope of a mere administrative tightening up of the program. Training slots are permanently lost to Job Corps. This means that the population Job Corps can serve will be substantially reduced.

Third, over 20 years of taxpayers' investment into these facilities will be lost. Expert and experienced staff will exit the program.

These facts underscore the short-sightedness of the Administration's plans to close Job Corps Centers. Moreover, while the passage of the Gramm-Rudman-Hollings Act may have altered decisionmaking in Washington, D.C., it has in no way diminished the effectiveness of the Job Corps, as yet, nor reduced the level of youth unemployment, nor changed the fact that Job Corps is deficit-neutral.

Unless this subcommittee acts before July 1 of this year, it is likely that centers will close this summer, and a new precedent and mechanism will be in place to close additional Job Corps Centers in years to come.

There are alternatives to Job Corps center closings.

One, the first and most desirable means of restoring the 4.3-percent cut for this fiscal year is through an fiscal year 1986 supplemental appropriation of $27,500,000.

This amount would simply return the program to the current services level for fiscal year 1986 adopted last year by Congress. We firmly believe that the Job Corps success rate and cost-benefit ratio overwhelmingly justify this approach.

A second and somewhat less desirable approach would be to enact a smaller fiscal year 1986 supplemental appropriation for Job Corps of $17,500,000. At this level, it is estimated that no centers would be required to close. We project that there are one-time overhead savings which could be made this year amounting to approximately $10,000,000.

The third and, in my view, least attractive alternative which I offer for your consideration would require no supplemental appropriations, but would represent a significant setback in our efforts to make sorely-needed capital improvements to Job Corps facilities.

This approach involves directing the Labor Department to delay temporarily certain capital improvements and to use for programmatic purposes instead a portion of the fiscal year 1986 funds now budgeted by DOL for capital needs. This would avert the necessity for center closings.

While the Job Corps community is virtually unanimous in its support of the first alternative, restoring the full 4.3-percent cut through a supplemental appropriation, we would prefer any of these alternatives to center closings.

In this regard, we urge you to adopt one of these options before July 1; otherwise, center closings will become a permanent reality, and Congressional discretion, as a practical matter, will be lost.

With respect to fiscal year 1987, there is no desirable alternative to a current services level of $665,500,000. The table that I have provided highlights the impact of various funding levels on Job Corps in fiscal year 1987.

What is important about these figures is that the immediate problem of Job Corps center terminations and cutbacks in available training slots will be exacerbated even at the original fiscal year 1986 funding level of $640,000,000.

At this level, it is projected that 4,000 fewer youth will be served, an additional three to seven centers will close, and several hundred staff will be laid off. A current services funding level will assure a stable future for Job Corps.

Mr. Chairman and members of this subcommittee, thank you for the opportunity to present these facts to you. I know that the entire Job Corps community will be grateful for your leadership to bring us through another very difficult year.

Mr. NATCHER. Thank you, Mr. Robinson. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Robinson follows:]

STATEMENT

OF

ROBERT ROBINSON
Center Director
Westover Job Corps Center

on

JOB CORPS
TITLE IVB OF THE
"JOB TRAINING PARTNERSHIP ACT"

before the

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES AND EDUCATION APPROPRIATIONS

U.S. House of Representatives

Chairman
The Honorable William Natcher

April 30, 1986

Mr. Chairman and respected members of the House Subcommittee on Labor, Health and Human Services and Education Appropriations, I am Robert Robinson, Center Director of the Westover Job Corps Center in Chicopee, Massachusetts. My employer, the RCA Service Company, has operated Job Corps centers since 1965. My personal experience with the program dates to 19 . I am honored to present this statement to you today on behalf of many business, labor and volunteer organizations associated with Job Corps. An up-to-date listing of the strong supporters of Job Corps is included in my statement.

Mr. Chairman, you and my distinguished congressman from Massachusetts, Mr. Conte, recognize how far Job Corps has come in over 20 years of operation. Through experimentation and innovation, Job Corps has been able to capitalize on its initial mistakes. Our early failures taught us that conventional approaches to education and training did not succeed with the Job Corps population. And so, we developed and perfected a residential, open-entry, open-exit, vocational and basic education model that is effective. Job Corps now enjoys well-deserved respect from the American public and the Congress. It is sadly ironic that today, Job Corps must fight harder than ever to justify its continuation and, most immediately, to avert center closings this summer.

On this note, I would like to highlight the two major themes of my testimony:

1. Job Corps needs the leadership of this Committee to overturn the Administration's plans to close 2-8 Job Corps Centers starting July 1, 1986.

2. Job Corps needs a current services funding level of $665.6 million in Fiscal Year 1987.

With respect to center closings, there are grave concerns. Purportedly, the Administration intends to close the "high cost, low performing" centers as a management tool to increase the program's overall unit cost efficiency. This rationale is flawed. First, unacceptably high cost centers or low Job Corps center performance should be corrected through proper program administration, not through center terminations. Second, center closings go beyond the scope of a mere administrative "tightening up" of the program. Training slots are permanently lost to Job Corps. This means that the population Job Corps can serve will be substantially reduced. Third, over twenty years of taxpayers' investment into these facilities will be lost. Expert and experienced staff will exit the program.

These facts underscore the short-sightedness of the Administration's plans to close Job Corps centers. Moreover, while the passage of the Gramm-Rudman-Hollings Act may have altered decision-making in Washington, DC, it has in no way diminished the effectiveness of the Job Corps (as yet), nor reduced the level of youth unemployment, nor changed the fact that Job Corps is deficit-neutral. Unless this Subcommittee acts before July 1 of this year, it is likely that centers will close this summer and a new precedent and mechanism will be in place to close additional Job Corps centers in years to come.

There are alternatives to Job Corps center closings.

1. The first and most desirable means of restoring the 4.3% cut for this fiscal year is through an F.Y. 1986 supplemental appropriation of $27.5 million. This amount would simply return the program to the current services level for F.Y. 1986 adopted last year by Congress. We firmly believe that the Job Corps success rate and cost/benefit ratio overwhelmingly justify this approach.

2. A second and somewhat less desirable approach would be to enact a smaller F.Y. 1986 supplmental appropriation for Job Corps of $17.5 million. At this level, it is estimated that no centers would be required to close. We project that there are one-time overhead savings which could be made this year amounting to approximately $10 million.

3. The third and, in my view, least attractive alternative which I offer for your consideration would require no supplemental appropriations, but would represent a significant set-back in our efforts to make sorely-needed capital improvements to Job Corps facilities. This approach involves directing the Labor Department to delay temporarily certain capital improvements and to use for programmatic purposes instead a portion of the F.Y. 1986 funds now budgeted by DOL for capital needs. This would avert the necessity for Center closings.

While the Job Corps community is virtually unanimous in its support of the first alternative -- restoring the full 4.3% cut through a supplemental appropriation -- we would prefer any of these alternatives to center closings. In this regard, we urge you to adopt one of these options before July 1; otherwise, center closings will become a permanent reality, and Congressional discretion, as a practical matter, will be lost.

With respect to Fiscal Year 1987, there is no desirable alternative to a current services level of $665.5 million. The table below highlights the impact of various funding levels on Job Corps in Fiscal Year 1987.

Funding Level	Service Years Produced	Service Year Reduction	Center Closings	New Enrollments	Total Participants
(in millions)					
$665.6*	40,544	0	0	70,000	110,544
$640	39,150	- 1400	3 - 7	67,400	106,550
$612.5**	37,650	- 3144	6 - 10	64,600	102,000
$600	36,650	- 3894	7 - 13	63,300	99,950
$575	35,200	- 5344	11 - 18	60,800	96,000
$550	33,700	- 6844	14 - 22	58,200	91,900
$500	30,750	- 9794	20 - 32	53,100	83,850
$450	27,800	- 12744	25 - 42	48,000	75,800
$352***	22,000	- 18544	38 - 64	38,000	60,000

* Fiscal Year 1987 Current Services Level
** FY '86 Appropriations Level minus 4.3% Gramm-Rudman cut
*** FY '87 Job Corps budget - proposed by President

What is important about these figures is that the immediate problem of Job Corps center terminations and cutbacks in available training slots will be excacerbated even at the original F.Y. 1986 funding level of $640 million. At this level it is projected that 4,000 fewer youth will be served, an additional 3-7 centers will close, and several hundred staff will be laid off. A current services funding level will assure a stable future for Job Corps.

Mr. Chairman and members of this Subcommittee, thank you for the opportunity to present these facts to you. I know that the entire Job Corps community will be grateful for your leadership to bring us through another very difficult year.

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The following business, labor and volunteer organizations are committed to the Job Corps and seek continued full funding for the program during F.Y. 1986 and F.Y. 1987:

Home Builders Institute
RCA
Singer
Teledyne
ITT
Management and Training Corporation
Coyne American Institute
Texas Education Foundation
Res-Care, Inc.
Training Management Resources
YWCA of Los Angeles
SER-Jobs for Progress
Intelcom Services, Inc.
Women In Community Service
MINACT, Inc.
Joint Action Community Service
Vinnell Corporation
Grand Rapids Public Schools
Tuskegee Institute
Training and Development Corporation
Aurora Associates, Inc.
Wackenhut Services, Inc.
Leo A. Daly
Alpha Kappa Alpha
AFL-CIO International Brotherhood of Painters and Allied Trades
AFL-CIO International Union of Operating Engineers
AFL-CIO Appalachian Council
AFL-CIO United Auto Workers
United Brotherhood of Carpenters and Joiners
National Maritime Union - Treasure Island Job Corps
International Masonry Institute
National Plastering Industry's Joint Apprenticeship Trust Fund
Brotherhood of Railway and Airline Clerks (AFL-CIO)
Commonwealth of Puerto Rico
Cherokee Nation of Oklahoma
University of Nevada-Reno
Pacific Education Foundation
Tribal Council of the Confederated Salish and Kootenai Tribes
of the Flathead Indian Reservation

WEDNESDAY, APRIL 30, 1986.

CSBG

WITNESS

ROBERT ZDENEK, PRESIDENT, NATIONAL CONGRESS FOR COMMUNITY ECONOMIC DEVELOPMENT

Mr. NATCHER. Our next witness is Mr. Robert Zdenek. Come around Mr. Zdenek.

Mr. ZDENEK. Mr. Chairman, the National Congress for Community Economic Development (NCCED), a national membership association of over 130 community-based development corporations, is pleased to submit testimony on behalf of the need to continued appropriation for the Community Services Block Grant and its Secretary's Discretionary Fund.

Mr. Chairman, I would like to take a moment to express my sincere appreciation and gratitude to you for your continuing efforts on behalf of the discretionary fund. Without your support and interest, organizations such as ours, and many others would not be able to maintain our efforts for those in need of our services.

I would respectfully urge that this committee provide funding at a level no less than fiscal year 1986 for both the Community Services Block Grant, approximately $360 million, and the full 9 percent for the Secretary's Discretionary Fund that will enable approximately $18.5 million to be allocated for significant CED programs.

I realize that in this time of fiscal austerity and Gramm-Rudman-Hollings, it is difficult to provide for the full authorization. However, the Community Services Block Grant and discretionary fund have been remarkably successful programs that create jobs and provide other economic resources for economically distressed communities.

The discretionary fund of the Community Services Block Grant (CSBG) is unique. It is the only Federal program designed exclusively to promote community business development and jobs in economically distressed areas. The few remaining Federal programs designed to provide economic development—HUD's Urban Development Action Grants (UDAG), EDA grants and the SBA have been substantially reduced, and under the President's fiscal year 1987 budget are slated for elimination.

Yet even if these programs were fully funded, the goals and nature of the population served by these programs differ from those of the discretionary funds. HUD and EDA require public bodies as applicants and neither are well-targeted to economically distressed or rural areas. SBA provides only loans or loan guarantees which are, by themselves, of little or no use to impoverished areas. The aim of the discretionary fund, unlike other federal programs, is to promote nonprofit community development corporation efforts which in turn stimulate economic growth. Funds are used to provide venture capital to develop businesses, develop or rehabilitate housing, renovate commercial and industrial facilities, provide technical assistance and training and cultivate networks among low income people, financial institutions and community leaders.

The success of a small amount of Federal seed money has been remarkable. Federal investment has created thousands of jobs, at little cost, and in areas of the country hit hardest by unemployment. In 1983 the Office of Community Services (OCS), with $18.8 million funded 42 projects across the country. Three thousand new jobs were created at a cost of $6,300 per job. In 1984, with Federal funding of only $18.76 million, the OCS predicted that 42 grantees would be able to develop 3,800 new jobs. In fact, 4,858 new jobs were created at a cost of only $3,849 per job. And in 1985, the OCS expects 36 funded projects to create 3,710 new jobs at a cost of $4,641 per job. This from a Federal investment of only $17.22 million.

Projects selected for funding create new businesses in areas of the country which some may have thought unable to rebuild—either too poor, too old or too rural to attract employers. The jobs created are useful ones and have a future. Projects funded include industrial rehabilitation, commercial development and construction, retail construction, manufacturing, training and community services. [See attached chart for type of projects funded by fiscal year.)

The discretionary fund has helped hundreds of local communities across the country. Four of the most successful programs are the Northern Community Investment Corporation in St. Johnsbury, Vermont; Eastside Community Investment, Inc. in Indianapolis, Indiana; Community Development Corporation of Kansas City in Missouri, and the Mountain Association for Community Economic Development in Kentucky.

NCIC serves six rural impoverished counties of northern Vermont and New Hampshire. The 185,000 people who live in these counties are chronically unemployed, underemployed or dependent upon public assistance. Yet over its nine-year life span, NCIC has invested in 127 businesses and 12 housing projects using $10.2 million in Federal, private and public funds to leverage $43.7 million.

NCIC's projects have generated or sustained 1,461 jobs. The corporation functions as a financial alternative and catalyst for entrepreneurs and businesses, provides technical assistance, and helps to create links in the local communities between banking and business people.

For example, an equity investment by NCIC of $950,000 leveraged almost $2 million in private and Federal funds, enabling a closed shoe plant in Lisbon, New Hampshire to reopen. The company initially hired 175 unemployed area residents, and today the annual payroll of $2.5 million supports 272 employees. In one economically depressed area, a large factory complex had long stood abandoned. An NCIC subsidiary purchased and rehabilitated it, selling it to a major casting manufacturer which has subsequently hired 220 people. Another top priority of NCIC is the creation of housing. With another subsidiary, NCIC has developed a community care facility providing rooms, meals and services to 278 low and moderate income elderly residents.

Eastside Community Investments. Inc. focuses on "self-help redevelopment" in a community where unemployment has been as high as 16 percent, and 75 percent of the families earn less than the county's median income. ECI has a development strategy, promoting business development and housing rehabilitation. With a $350,000 grant from OCS, ECI was able to leverage an additional $860,000 and turn a closed elementary school into a 24-unit apartment building for low income people. Over the life of the project, 27 people in the hard pressed construction industry were employed. ECI has also begun development on an industrial park which will not only help retain 100 existing jobs, but create 310 permanent jobs as well.

The Community Development Corporation of Kansas City serve an inner-city low income predominantly black community. They have undertaken a wide range of housing, commercial, job training, and business development initiatives to help revitalize their community. CDCKC received $500,000 from the OCS Secretary's Discretionary Fund in 1985 to develop a 150,000 square foot shopping center in the inner city of Kansas City which provided 239 construction jobs and 150 permanent jobs, while providing needed services to community residents.

OCS funds have leveraged a $2.5 million loan from the Prudential Life Insurance Company, $550,000 syndication, $100,000 grant from the city, a $150,000 grant from the Hallmark Foundation, and $300,000 of equity from the CDC. The shopping center which is named Linwood will be the first shopping center constructed in a low income neighborhood in Kansas City.

Communities in the poor, rural areas of central Appalachia have a different set of problems. Many people are unemployed or work only part of the year at low income jobs in the local hardwood industry. These industries do not have the financial capabilities or expertise to expand the marketing of their products. Because of the uncertain nature of employment, many people cannot afford proper housing. MACED is developing community-wide, long-term strategies to address these issues. With a $685,000 grant from OCS, MACED was able to leverage over an additional $1 million. This money was used to form a new lumber company, is developing markets for small local mills, provides them with technical assistance, and employs 40 people. MACED also was instrumental in forming a consortium of 94 banks in eastern Kentucky which are now committed to providing long-term, low down payment mortgages.

Mr. Chairman, I must raise another concern. In the past two years, the administration has taken monies from the discretionary fund, specifically from community economic development activities, for aid to two homeless shelters in D.C. Although we strongly support activities to develop adequate housing for homeless individuals, we do not believe that the monies should be taken from the discretionary fund The grants made both in fiscal year 1985 and the current fiscal year were not made via the competitive process.

In addition, activities undertaken by these grants, although worthwhile, are not consistent with either the intent or the spirit of the law. If the discretionary fund is to remain viable, it is critical that this administration preserve the integrity of the fund and that grant funds be awarded based on competitive criteria.

Mr. Chairman, we thank you and other members of the subcommittee for considering the testimony of the National Congress for Community Economic Development. We applaud the subcommittee for convening hearings on the reauthorization of the CSBG and Secretary's Discretionary Fund.

[The statement of Mr. Zdenek follows:]

WRITTEN TESTIMONY

Submitted By

THE NATIONAL CONGRESS FOR COMMUNITY ECONOMIC DEVELOPMENT

Robert Zdenek, President

ON

APPROPRIATIONS FOR THE COMMUNITY SERVICES BLOCK GRANT
SECRETARY'S DISCRETIONARY FUND

Presented to the

HOUSE APPROPRIATIONS COMMITTEE

SUBCOMMITTEE ON LABOR, HHS, AND OTHER RELATED PROGRAMS

Honorable William Natcher (D-KY), Chairman

April 30, 1986

3:35 P.M.

Mr. Chairman, the National Congress for Community Economic Development (NCCED), a national membership association of over 130 community-based development corporations, is pleased to submit testimony on behalf of the need to cotinued appropriation for the Community Services Block Grant and its Secretary's Discretionary Fund.

Mr. Chairman, I would like to take a moment to express my sincere appreciation and gratitude to you for your continuing efforts on behalf of the discretionary fund. Without your support and interest, organizations such as ours, and many others would not be able to maintain our efforts for those in need of our services.

Yet, we realize, Mr. Chairman, that it is largely due to your effort on this Committee that we have been able to continue the worthwhile programs of the discretionary fund. I would respectfully urge that this Committee provide funding at a level no less than fiscal year 1986 for both the Community Services Block Grant, approximately $360 million, and the full 9% for the Secretary's Discretionary Fund that will enable approximately $18.5 million to be allocated for significant CED programs. I realize that in this time of fiscal austerity and Gramm-Rudman-Hollings, it is difficult to provide for the full authorization. However, the Community Services Block Grant and discretionary fund have been remarkably successful programs that create jobs and provide other economic resources for economically distressed communities.

The discretionary fund of the Community Services Block Grant (CSBG) is unique. It is the only federal program designed exclusively to promote community business development and jobs in economically distressed areas. The few remaining federal programs designed to provide economic development -- HUD's Urban Development Action Grants (UDAG), EDA grants and the SBA have been substantially reduced, and under the President's FY 1987 budget are slated for elimination. Yet even if these programs were fully funded, the goals and nature of the population served by these programs differ from those of the discretionary funds. HUD and EDA require public bodies as applicants and neither are well-targeted to economically distressed or rural areas. SBA provides only loans or loan guarantees which are, by themselves, of little or no use to impoverished areas. The aim of the discretionary fund, unlike other federal programs, is to promote non-profit community development corporation efforts which in turn stimulate economic growth. Funds are used to provide venture capital to develop businesses, develop or rehabilitate housing, renovate commercial and industrial facilities, provide technical assistance and training and cultivate networks among low-income people, financial institutions and community leaders.

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The discretionary fund has helped hundreds of local communities across the country. Four of the most successful programs are the Northern Community Investment Corporation (NCIC) in St. Johnsbury, Vermont; Eastside Community Investment, Inc. (ECI) in Indianapolis, Indiana; Community Development Corporation of Kansas City (CDCKC) in Missouri, and the Mountain Association for Community Economic Development (MACED) in Kentucky.

NCIC serves 6 rural impoverished counties of northern Vermont and New Hampshire. The 185,000 people who live in these counties are chronically unemployed, underemployed or dependent upon public assistance. Yet over its 9-year life span, NCIC has invested in 127 businesses and 12 housing projects using $10.2 million in federal, private and public funds to leverage $43.7 million. NCIC's projects have generated or sustained 1,461 jobs. The corporation functions as a financial alternative and catalyst for entrepreneurs and businesses, provides technical assistance, and helps to create links in the local communities between banking and business people. For example, an equity investment by NCIC of $950,000 leveraged almost $2 million in private and federal funds, enabling a closed shoe plant in Lisbon, New Hampshire to reopen. The company initially hired 175 unemployed area residents, and today the annual payroll of $2.5 million supports 272 employees. In one economically depressed area, a large factory complex had long stood abandoned. An NCIC subsidiary purchased and rehabilitated it, selling it to a major casting manufacturer which has subsequently hired 220 people. Another top priority of NCIC is the creation of housing. With another subsidiary, NCIC has developed a community care facility providing rooms, meals and services to 278 low and moderate income elderly residents.

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Community economic development monies provided by the CSBG's discretionary fund are of vital importance to communities across the country. With a small federal investment, community based organizations are able to develop a comprehensive approach for the economics, political and social revitalization of their areas. Despite economic and political obstacles, these organizations have been able to achieve significant accomplishments in job creation, housing development, service delivery, institution building and economic and political empowerment for low and moderate income people.

Mr. Chairman, I must raise another concern. In the past two years, the administration has taken monies from the discretionary fund, specifically from community economic development activities, for aid to two homeless shelters in D.C. Although we strongly support activities to develop adequate housing for homeless individuals, we do not believe that the monies should be taken from the discretionary fund. The grants made both in fiscal year 1985, and the current fiscal year were not made via the competitive process. In addition, activities undertaken by these grants, although worthwhile, are not consistent with either the intent or the spirit of the law. If the discretionary fund is to remain viable, it is critical that this administration preserve the integrity of the fund and that grant funds be awarded based on competitive criteria.

Mr. Chairman, we thank you and other members of the Subcommittee for considering the testimony of the National Congress for Community Economic Development. We applaud the Subcommittee for convening hearings on the reauthorization of the CSBG and Secretary's Discretionary Fund.

Types of Projects Funded by the Discretionary Fund FY's '83-'85

	1983	1984	1985
Industrial Rehabilitation	10	12	6
Commercial Construction	9	13	12
Commercial Development/ Retail Construction	5	9	4
Manufacturing	12	3	7
Training	1	3	3
Community Services	6	2	4

Mr. NATCHER. Thank you, Mr. Zdenek, you have made an excellent statement, and we appreciate your appearance.

WEDNESDAY, APRIL 30, 1986.

EMPLOYMENT SERVICES

WITNESS

BILL HEARTWELL, EXECUTIVE VICE PRESIDENT, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES

Mr. NATCHER. Our next witness is Mr. Bill Heartwell. We are glad to have you back before the committee again. We are pleased to hear from you.

Mr. HEARTWELL. Thank you, Mr. Chairman.

In deference to the late hour and time restraints that you have been facing today, we will make a very brief statement as we have already submitted our written testimony for the record. We do represent the Interstate Conference of Employment Security Agencies which is the organization that represents the Administrators of Employment Service and the Unemployment Insurance Service for the country.

We have appeared before this committee on many occasions and we have always found it most supportive and aware of the needs for additional funding for employment service, unemployment insurance, for automation, for non-personnel services and we want to thank you for his past support and also that of your staff in helping us analyze and document these needs.

This year in spite of an increased need and necessary funding for the employment and for unemployment insurance service to maintain our current level of funding and to provide additional services to employers and to unemployed, in spite of this and in spite of the fact, Mr. Chairman, that there is a very healthy surplus in the employment security administrative account, we are cognizant of and sensitive to the Balanced Budget and Emergency Deficit Control Act of 1985, and we are committed to provide the wide range of employment services and unemployment insurance services to our constituents within the boundaries of the Administration's submitted fiscal year 1987 budget.

We are asking for no increase, Mr. Chairman, but we hasten to add that we would like to emphasize that we think unless Congress does pass an appropriation bill, and if there is an additional sequestration in 1987, that this would create a chaotic situation that the Job Service as a viable labor exchange would be terminated and that the integrity of our unemployment insurance system we think would be severely compromised.

We base this on the fact that of a survey of our States with 32 responding to date that additional sequestration in the range of 20 percent in 1987 would close at least 350 additional local offices and would reduce the combined ESUI staff by 7,500 additional.

Just looking at the employment service with the funding reductions that it took in 1985, along with the—1982 along with the reduction this year of Gramm-Rudman and with this potential cut of additional sequestration, it could mean as much as 40 to 50 percent reduction in employment service funding in the past five years and we think again this would be devastating.

So our request, Mr. Chairman, is to help us maintain the stability of the current funding in the years ahead so that we can continue to provide the diverse services that we are providing to millions of Americans.

I would mention two other instances, programs of which we would request some assistance from this committee. The first is the Trade Adjustment Assistance Act which was just actually continued until 1991 by the Congress. This Act for the first time has a job section component that would require recipients of trade adjustment assistance to actively seek jobs and we feel like that the employment service will be actually designated as the operational program to provide this assistance if no money was provided until this Act was continued until 1991.

We would request that the committee take a good look at this inasmuch as adding additional burdens on the present system, of course, would impact on the services we provide to our clientele.

In the area of unemployment insurance, we would request from the committee to provide the States with additional flexibility in two areas. One would be to prevent the Department of Labor from the quarterly recapture of funds. By recapturing funds from the States, each quarter it prevents the States from planning for a full year and we think language, the language in the appropriations bill, has been misinterpreted by the Department of Labor and this could be cleared up administratively.

Secondly, also we feel that when States do affect savings with appropriated monies that they should be permitted to carry the savings over from one year to the next rather than to have these funds taken away.

This does conclude my testimony. Again, we appreciate this opportunity and we will be looking forward to working with the subcommittee and the staff in the future and trust you will call on us if we can be of any assistance.

Mr. NATCHER. Thank you very much, Mr. Heartwell. You have given us an excellent statement.

We have two witnesses and a roll call vote. I am going over and vote and I will come right back and we will complete the testimony for the afternoon.

[Recess.]

[The statement of Mr. Heartwell follows:]

ICESA

STATEMENT

OF THE

INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

ON

APPROPRIATIONS FOR UNEMPLOYMENT INSURANCE AND
EMPLOYMENT SERVICE OPERATIONS

TO

COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR-HEALTH AND
HUMAN SERVICES-EDUCATION

BY

WILLIAM L. HEARTWELL, JR., EXECUTIVE VICE PRESIDENT
INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

APRIL 30, 1986

Mr. Chairman, members of the Subcommittee, my name is William L. Heartwell, Jr., I am Executive Vice President of the Interstate Conference of Employment Security Agencies (ICESA), Inc. ICESA is the organization representing administrators of state unemployment compensation laws and public employment service offices throughout the country. We appreciate this opportunity to present our views concerning FY 1987 appropriations for the programs our members administer.

In the past, we have requested your support for additional staff for both employment services and unemployment insurance, for additional funds for automation, and for increased non-personal services resources. You and your staff have been diligent and helpful in investigating our arguments for these additional funds, and we appreciate the support this Subcommittee has given us over the years.

This year, we recognize the constraints placed on the FY 1987 appropriations process by the Balanced Budget and Emergency Deficit Control Act of 1985. Therefore, even though our system still badly needs funds to better serve employers and unemployed workers, and even though there is a healthy balance of federal unemployment taxes collected for this purpose, we are committed to accomplishing the basic functions of the employment security system within resources requested in the President's FY 1987 budget.

More specific comments about the major components of the employment security system are provided below:

EMPLOYMENT SERVICE

The first sequestration order, which became effective March 1, actually will impact on Employment Service operations for Program Year 1986 which runs from July 1, 1986, through June 30, 1987. ES funds were reduced by $34M, bringing Program Year 1986 funding down to $758.1M. This represents a reduction of $19.3M from our current Program Year operating level of $777.4M.

Based on a recent survey of State Employment Security Agencies, we can definitely report that as a result of losing funds there will be further reductions in service levels directly caused by the closing of offices as well as staff cuts. Information provided by 32 states to date indicate we will close 73 local offices and eliminate over 900 positions. We estimate ES staffing will drop to a level of approximately 21,500. It is important to note in this regard, that the Employment Service has already undergone severe reductions in staffing and service delivery resulting from the 1982 appropriations process. At that time we were forced to reduce ES staffing from 30,000 to 22,800 and to close 200 offices. As a result of this action we are deeply concerned over the devastating impact that another sequestration would have on the system and the diverse services it provides. We firmly believe that if a second round of cuts were effected in the range of 15-25%, states would again be faced with closing much of their operations and a viable national labor exchange would cease to exist. A reduction of this magnitude from the reports of the same 32 states previously mentioned, indicate that the system would lose an additional 3,000 ES staff and close another 350 local offices.

We also feel it is important to recognize the current services being provided by the states in the employment and training area in serving two major categories of workers that are experiencing difficulty in obtaining gainful employment in today's economy.

We are referring to youth and the dislocated worker. Of the 3.5 million persons the employment service placed into jobs, we estimate approximately 40% are youth under 22 years of age.

Regarding assistance to dislocated workers, the coordination between the employment service and the JTPA system indicates that 45 state employment security agencies have administrative and/or operational responsibilities in the Title III JTPA Dislocated Worker Program.

We mention the above only to emphasize that further cuts would seriously impair vital services in these most important areas.

(For your information we have attached to our testimony a summary productivity report for PY 1984, the last full year operating period in which data is available.)

We are also concerned about funding for two additional programs that are administered by our system: Trade Adjustment Assistance (TAA) and the Targeted Jobs Tax Credit (TJTC). TAA was recently reauthorized by Congress, and extension of the TJTC Program is included in both the House and Senate tax reform measures. The President's budget, however, assumes termination of both programs and provides no administrative resources.

As you know, the Trade Adjustment Assistance (TAA) Program was recently extended to 1991, as part of the FY 1986 budget reconciliation bill. A major change in the employment and training provisions mandates that recipients participate in an approved job search program. As you consider the level of funds needed for TAA, we request that you include an adequate amount for administration, including the additional resources that will be required to manage the mandated job search portion.

Another area for your consideration, concerns administrative funds for the Targeted Jobs Tax Credit (TJTC) Program. Even though the Program expired December 31, 1985, Congressional interest in extending and modifying the Program remains strong. Specifically, both the House-passed tax reform bill and the Senate Finance Committee tax reform plan include an extension of TJTC. In addition, there continues to be significant interest and support to pass a temporary extension of the Program, including a retroactive provision. Our primary concern with all of this TJTC activity is to ensure that the State Employment Service System receives adequate administrative funds to fulfill its responsibilities as the statuatorily designated certifying agency.

From a recent survey of State Employment Security Agencies, we have learned that the Fiscal Year 1985 appropriation of $27.5M for TJTC administration provided less than half of the required costs. State agencies had to divert scarce Employment Service staff to keep pace with the processing requirements. Our information actually reveals that, on average, State TJTC allocations lasted only four months.

Over the past few months, employers have been contacting our agencies in unprecedented numbers, in anticipation of an extension of the TJTC Program, and particularly a provision which would make the Program retroactive to January 1, 1986. The employer's message is clear: they have continued to hire TJTC eligibles and expect the State agency to expeditiously process the requests for vouchers and certifications that will be forthcoming in large volumes immediately following the passage of an extension. Quite frankly, the states will not be able to meet this demand without adequate administrative funds.

UNEMPLOYMENT INSURANCE

The President's budget for FY 1987 would restore most of the cuts to UI that resulted from the FY 1986 Gramm-Rudman-Hollings sequestration order. Shortages of funds in areas such as non-personal services and automation would still exist at this level of funding, however, we believe that additional flexibility in the use of funds would permit us to continue to provide adequate services to unemployed workers in FY 1987.

If the sequestration process were to take effect in FY 1987, the ability of the UI System to meet its responsibilities to unemployed workers would be compromised. A survey of state employment security agencies, with 32 reporting, shows an estimated reduction in staff of about 4,500 if the cut was 20%. In addition, local offices would be closed in 350 locations in those 32 states. The effects of such a severe reduction would be so devastating that it is difficult to project just what would happen. There would likely be delays in processing claims, more erroneous payments, and fewer taxes collected.

As you know, the Department of Labor has initiated a review of administrative financing of the unemployment insurance system. Public meetings were held this past January. Both oral and written comments were solicited from all interested parties; ICESA's comments are attached for your information. The Department is continuing discussions with an advisory group made up of representatives of business, labor, states and the public.

Several of the changes which we recommended to DOL we also recommend to you because they involve changes in the language of appropriation bills that would give states greater flexibility in managing scarce resources. First is elimination of the requirement that normal budgetary adjustments be made quarterly. There is appropriation language which makes contingency funds available "only to the extent necessary ... (for certain purposes) ...which cannot be provided for by normal budgetary adjustments." The last phrase has been interpreted to require the Department of Labor to recapture any unspent funds at the end of each quarter. This has had the effect of forcing states to budget on a quarterly rather than an annual basis, restricting the ability to plan and manage resources most effectively.

Our second recommendation is that funds appropriated in one fiscal year be available for expenditure during that year and the following fiscal year. This would permit states to use any savings they were able to achieve during one fiscal year toward capital expenditures the following year.

In order to maintain our current level of services to unemployed workers within the resources requested in the President's budget, we need as much flexibility as possible in managing these resources. Therefore, we urge you to restrict application of budgetary adjustments to the end of the fiscal year and to permit appropriated funds to be spent over two years.

LABOR MARKET INFORMATION

A vital component of the Employment Security system is the Labor Market Information program which provides data to assist the Unemployment Insurance/Employment Service operation and support state/local planners in evaluating labor market conditions. As the workplace becomes more technologically advanced and the labor force more sophisticated via enhanced education efforts, information on labor market opportunities in relation to economic development will be more and more important. We will continue our efforts in further improving the major contributions we are making as labor market analysts.

In conclusion, our organization remains dedicated to improving the public programs that we offer at no charge to our clients--employers looking for workers, the unemployed in transition to reemployment, and information on this labor exchange process. Thank you for this opportunity to present our views. I will be happy to answer any questions that you may have.

AppTest.A9

The United States Work Force Served by the Employment Service (ES) Program Year 1984

- The Employment Service is clearly the principal labor exchange agency in most U.S. communities. In many towns and localities with populations under 100,000 the Employment Service is the only labor exchange entity available to employers and workers.

- It is estimated that the Employment Service obtains between 12-15 percent of the 40 percent of the total job openings actually listed in the national labor market. The remaining 60 percent are filled by word of mouth, personal contacts, direct recruitment and advertising. The Employment Service then captures about 30 to 38 percent of the share of the total available market, at a cost of only about $780 million per year.

- The new and renewal applications in the Employment Service reflected 17,741,021 transactions indicating the registration of 16,034,192 individuals.

- Of the number registered, a positive service outcome (placement in job/training) was experienced by 3,576,775 individuals. Other services were rendered to 5,933,782 persons (counseling, testing, job development) to reflect a total of some services to 9,510,557 individuals.

- Of the total placement transactions of 5,081,599, direct placement in jobs benefited 3,480,077 individuals or 68.5 percent.

- Demographically, the Employment Service placements were: 1,984,654 or 57 percent males; 1,496,048 or 43 percent females. Minorities constituted 35.4 percent of Employment Service placements (Blacks 23.7%; Hispanics 9.3%, American Indians .9%).

SOURCE: USES, U.S. Department of Labor.

- Applicant groupings of Employment Service placements were:
  - Veterans - 13.7 percent
  - Displaced workers - 2.8 percent
  - Welfare - 4.6 percent
  - WIN applicants - 2.3 percent
  - Handicapped - 3.4 percent
  - U.I. claimants - 15.7 percent
  - Youth percent - 38.6
- The Employment Service provided expanded placement related services to individuals:
  - Jobs obtained from ES job search or job finding clubs - 77,083;
  - Counseling - 621,108;
  - Testing - 648,971;
  - Enrollment in training 148,376;
  - Job development contacts - 1,374,179
  - Referral to other supportive services - 1,358,539.
- The Employment Service system also provided placement assistance to other applicant groups:
  - (TJTC) Targeted Jobs Tax Credit candidates totaled 1,342,951 vouchers and 621,889 certifications;
  - (MSFW) Migrant and Seasonal Farm Worker program served 152,839 new and renewal applicants;
  - (Older Workers) Services to older workers ages (40-54), 2,152,006 and ages 55 and over, 755,942 for a total of 2,907,948.
  - (TAA) Displaced Workers - Intake and assessment 38,441, counseling services 18,065 and job referrals 12,844, referrals to training 8,668.

UNEMPLOYMENT INSURANCE ADMINISTRATIVE FINANCING REFORM COMMENTS AND RECOMMENDATIONS

INTRODUCTION

The Social Security Act of 1935 established the Unemployment Insurance (UI) system with broad federal guidelines for coverage of workers, taxation, and benefit eligibility, leaving wide discretion for state-specific program design.

In recent years federal intervention into the details of the UI system has increased significantly. At a time when federal intervention in job placement programs and other social programs has been relaxed, new federal standards for UI benefits have been enacted (e.g., pension offset, waiting week, denial of benefits to professional athletes). These standards have limited/reduced the payment of UI benefits. During the same period, there have been reductions in administrative funds and tightened fiscal controls. The apparent result of this increased federal intervention in both benefits and administrative funding has reduced benefits for many eligible claimants and has reduced the number of individuals eligible for benefits and has denied states funds to maintain quality and to prevent fraud, waste and abuse.

In looking back, it becomes clear that a significant change in the attitude toward the benefit payment side of the program developed in 1967 when the decision was made that receipts of all trust funds held by the U.S. Treasury, including those of the states' UI benefits accounts, were to be incorporated in a unified Federal budget beginning in 1968. Since that date, expenditures from these funds (UI, Social Security, etc.) have been reflected in the total national budget. Reduced expenditures from trust funds improve the national budget balance, regardless of the dedicated nature of the trust funds themselves. In the instance of UI funds, monies raised solely by the states available, solely for the payment of unemployment benefits, are treated as if they were expenditures of federal funds. These dedicated funds, including the trust funds used for administration, should be removed from federal budget totals.

In addition to concern about increased federal intervention in the program, many states are concerned that the impact of administrative funding on the trust fund--both benefit payments and tax collections--is not recognized. Certain activities more than pay for themselves in benefit savings/recoupment or in increased tax revenues. This relationship should be acknowledged in the funding process.

The following comments address issues more directly related to administrative financing reform. The underlying objective of these recommendations is reduced federal intervention in the UI program.

SHORT-TERM PROPOSALS

Short-term proposals are those than can be implemented in the FY 1987 appropriation, allocation, and contingency funding processes. The focus of these proposals is increased flexibility in the management of inadequate resources.

A. Allocation Method. Due to short time frames, only two changes are proposed for the FY 1987 allocation process.

1. Base staffing should be on the basis of the average of the four quarters, not the low quarter.

The low quarter budget methodology creates inequities in the amount of funding provided to the states. It also creates a major problem of staffing each quarter in anticipation of rising or falling seasonal claimsload.

In addition to the total direct funding, the number of base staffyears determines by formula the amount of AS&T, NPS and Support staffyears and dollars in the total base budget. States with relatively larger seasonal swings will have base staff levels well below the yearly average staff levels. Since total funding for base staffyears is greater than for above-base contingency staffyears, states with broad seasonal swings will be awarded proportionately fewer dollars than states without significant seasonal factors.

The budget methodology should be revised so that the average staff rather than low quarter staff, is the base for allocation of base budget resources. This change will improve the quality, continuity, and integrity of program and budget management.

2. Revise the UI Salary Survey to tie salary rates to future budgeted positions, rather than the survey month positions.

Each year DOL requires a salary rate survey for UI. This determines the average salary to be used in calculating the personal services requirements for the next year.

The salary rate calculated based on the survey month will be factored against the next year's budgeted level of positions, even though that budgeted position level may be far different than the survey month position level. DOL never comes back and compares the budgeted level of positions with the survey month positions, and thus can either underfund or overfund a state. The over or underfunding is a result of the change in the mix of staff, and thus the average salary rate requirement, between the survey month and the future budget.

The Department of Labor should reevaluate the salary rate survey results once the budgeted level of positions is known, and make appropriate adjustments, upon consultation with the states.

B. Financial Management and Control. Substantial changes should be made in the contingency funding process and control of UI resources by the Department of Labor for FY 1987. The changes proposed below would improve states' ability to plan and manage their resources:

1. States should be reimbursed for earned staff whether used or not and these staff earnings should not be subject to recapture.

The states, through their detailed Cost Model Studies, have demonstrated the level of funding required to perform the basic UI functions. During the budget process, these time factors have been arbitrarily cut. The states are then subjected to quarterly balancing acts in order to avoid over or underutilization of staff, with "surplus" staff resources recaptured and overspending left unfunded. There are no incentives to save staff time since such a savings will be recaptured.

The states should be allowed to retain all staff time earned, without regard to the actual usage or the quarter in which variances occurred. The resources freed from daily budget balancing could be used to increase program quality, more effectively manage the program and make productivity improvements without the fear of losing resources.

This practice would permit states flexibility in the use of resources among various budgeted staff categories. For example, staff could be moved between benefits and tax without affecting contingency funds and staff resources could be used for nonpersonal services (NPS) without penalty. This means that staff and overhead resources would be interchangeable.

2. States should permitted to use staff that are not necessary to accomplish specific functions (e.g., cost model, quality control) for other activities.

   The only concern of the Department of Labor should be whether a specific function is accomplished, not the number of staff assigned to it.

3. Eliminate the quarterly recapture of unobligated balances.

   The normal budgetary adjustment (NBA) process unduly restricts the budgetary, fiscal, and operational flexibility of the states. Ninety-five percent of budget surpluses are recaptured by DOL. States are allowed to modify their budget plans prior to the start of the quarter affected. This procedure does not protect the resources of a state when unforseen circumstances arise within a quarter.

   A more sensible approach would be to hold states harmless until the end of the year, allowing states to manage costs and staff within annual rather than quarterly timeframes. Better program management will result.

   In addition, beginning with FY 1987 funds, the appropriations language should be modificed to permit states to carryover unobligated balances from one fiscal year to the next.

4. The states' ability to absorb salary and law changes should take into consideration the total financial status of the program, not only salary rate savings.

   Before DOL will provide additional UI base funding, whether for legislatively approved salary increases or law changes, they will calculate the amount of salary rate savings a state may have accrued and reduce this amount from their request. The logic for their adjustment is that the state was overfunded in the base budget, and contingency funds (the source of the salary and law reserve) cannot be used until base resources have been exhausted.

   The problem is that DOL does not look at the NPS or AS&T portions of the base budget. A state could have been underfunded by $1 million in NPS, thus the base budget has no excess resources, and yet because there may be salary rate savings, the valid salary and law reserve request is reduced or denied in total.

DOL must look at the entire UI program financial status of the particular state when considering whether a state has sufficient resources, not just rate savings.

5. Supplemental budget requests should be processed in a more timely fashion.

Delays in the federal processing of supplemental budget requests (including any mechanism that provides federal resources to the states) place the states in an environment of uncertainty while awaiting approval or disapproval. The natural reaction is for the state to be very conservative in spending, pending all but the highest priority purchases.

When supplemental budget request action is delayed, it may appear that the state is accumulating sufficient funds, through their conservative behavior, to offset a portion of the amount requested. The states should not be penalized for responding conservatively to funding delays, and the Department of Labor should make the review and approval of supplemental budget requess a higher priority.

C. Management Improvements. In addition to purely financial considerations, the following changes should be made that would improve federal-state relations in the management of the unemployment insurance program.

1. Desired levels of achievement should be reduced in number and/or modified to reflect reduced resources.

2. The Department of Labor should provide information concerning the use of all UI administrative funds, including federal administrative funds and state grants for national activities.

3. Resources provided to states for specific purposes should have minimum broad requirements and controls, leaving detailed decisions regarding implementation to the states.

INTERMEDIATE-TERM PROPOSALS

The following proposals are recommended for FY 1988 and beyond. They address the adequacy of funding as well as improved allocation methods.

1. Involve the states in formulation of the federal budget request.

   The Departmetn of Labor should work with the states in developing the Department of Labor's budget. This input will allow for the presentation of documentation in support of mutual goals in the development of accurate levels of resources necessary to serve the public by each program area.

   The federal/state partnership can be strengthened by providing a forum for the frank discussion of budgetary issues and the exchange of ideas. Perpetuation of the current top-down approach insulates USDOL administrators and stifles creativity and mutually beneficial solutions to problems.

2. The Cost Model studied MPU's should be funded.

   The rationale for MPU reductions by DOL is rooted in the budget cutting imperative. Rather than adequately finance current administrative costs and consciously guide and finance productivity improvements, MPU's are reduced to agree with federal budget targets. This arbitrary approach, fostered by a short-term savings mentality, discredits DOL's legitimate efforts to improve productivity. Unilateral productivity assessments usually result in a sacrifice of quality and not improved methods. This fact has been borne out by Random Audit studies. It undermines state faith in the federal/state partnership. It does nothing to improve cost efficiency. As long as the cost model is used, the unique state MPU's should be fully funded.

3. Nonpersonal Services requirements should be funded.

   The amount of funds requested by DOL and eventually allocated to the states for UI nonpersonal services (NPS) is not sufficient to cover the actual costs of the program. This forces the states to take action that ultimately affects program quality. Staff resources that are already reduced due to the effort to match the federal appropriation are further reduced to compensate for inadequate nonpersonal services funding. The states are also forced to make reductions in variable line items of the budget (i.e., travel, communications, supplies, etc.) because a greater proportion of the budget must be utilized to cover fixed costs, such as facilities and equipment.

The allocation methodology for distributing the NPS resources to the states has not kept pace with changes occurring within the individual states, and has not resulted in an equitable distribution of the limited resources.

Despite Congressional awareness that sufficient funds for UI NPS have not been provided to the states, as evidenced through supplemental NPS funding, these additional resources have not been added to the base budget for the ensuring years.

The Department of Labor should work with the states in an effort to develop a budget request to Congress that includes adequate nonpersonal services funding so that the need for states to balance the UI budget through extraordinary means affecting program quality is eliminated. Every effort should be made to request and obtain sufficient funds during the initial budget process, rather than rely on Congress to act on supplemental funding.

The Department of Labor should also involve the states in an effort to revise the allocation methodology of distributing UI nonpersonal services resources to the states, taking into consideration unique state geographic and operational environments, rather than as an historical relation to previous year's staff.

4. Reduce the wide variances in budget and rates between base and contingency staff.

The salary rates, benefit rates, nonpersonal services, UI support and AS&T rates for contingency staff are significantly below the base budget rates. This is due to the assumption that base funded staff are permanent and all above-base contingency staff are temporary. It also assumes that basic nonpersonal services, such as facilities, have been adequately funded in the base budget and therefore contingency resources are not needed.

Neither assumption is entirely correct. Permanent staff are often utilized to process contingency workloads, costing the same as their "base" counterparts, requiring adequate facilities, supplies, and the same administrative support. Nonpersonal services shortfalls in the base are an annual occurrence. The arbitrary and inadequate above-base rates neither fund the actual cost of the contingency staff, nor compensate for underfunding in the base budget.

The Department of Labor should join with the states to reevaluate the budgetary rates for contingency financing, reducing the wide variances from base rates and more adequately financing the actual costs incurred by the states.

5. Fund the negotiated indirect cost rates for administrative overhead (AS&T).

The states prepare annual indirect cost rates. They are negotiated and approved by the USDOL Office of Cost Determination. The purpose of the indirect rate is to provide a means of budgeting for state administrative overhead (AS&T).

The Employment and Training Administration has continuously failed to recognize and fund these negotiated rates for the UI program. The amounts provided are arbitrarily derived, and often disproportionately below the amounts recovered from other federal contracts and grants. This forces the states to either reduce all administrative overhead spending to the level the UI program can afford, or else overspend the UI's AS&T budget and reduce direct program expenditures.

The Department of Labor should utilize the vehicle designed to budget for administrative overhead (i.e., the indirect cost rate in accordance with OMB Circular A-87).

6. Direct UI program management should be fully funded.

The amount of resources provided for UI support (direct management of the UI program, supervision, training, etc.) is currently based on a percentage of base direct staff with a small addition based on contingency staff. Many of the support activities do not vary directly with the workload. Indeed, these needs may increase disproportionately as a large number of untrained individuals are recruited. Closer supervison and more training are required for overseeing the work of large numbers of people unfamiliar with normal operating and procedural requirements. The current allocation methodology does not take this into account, resulting in underfunding of UI support functions. The failure to provide sufficient resources for supervision, training and the ability to oversee the activities of quickly hired temporary staff undermines the effectiveness of the entire unemployment insurance system.

The Department of Labor should work with the states to design a more logical and equitable method of justifying and allocating resources for direct UI program management.

LONG-TERM PROPOSALS

Proposals for major changes in the administrative financing of the Employment Security System continue to be debated. There is a concern that the accumulation of excessive amounts in the Employment Security Administration Account should not continue. Funds collected for administration of the Employment Security System and needed by the states should be made available. Mechanisms for accomplishing this objective should be addressed jointly by the states and the Department of Labor.

Interstate Conference of Employment Security Agencies, Inc.
January 22, 1986

Mr. **Natcher**. We will insert at this point in the record the statement of Mr. Kamaki A. Kanahele.

[The statement of Kamaki A. Kanahele follows:]

STATE OF HAWAII
OFFICE OF HAWAIIAN AFFAIRS
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TESTIMONY BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION AND RELATED AGENCIES

RAYBURN HOUSE OFFICE BUILDING
ROOM 2358
WASHINGTON, D.C. 20515

SUBMITTED BY

OFFICE OF HAWAIIAN AFFAIRS
567 SOUTH KING STREET
HONOLULU, HAWAII 96813

Kamaki A. Kanahele III
Kamaki A. Kanahele, III
Administrator

April 30, 1986 - 3:45 P.M.

STATE OF HAWAII
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OFFICE OF HAWAIIAN AFFAIRS

TESTIMONY BEFORE THE U. S. HOUSE SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES AND EDUCATION AND RELATED AGENCIES
WEDNESDAY, APRIL 30, 1986, 3:45 P. M.
RAYBURN HOUSE OFFICE BUILDING, ROOM 2358

Good afternoon Mr. Chairman and members of the Committee. I would like to thank Congressman William Natcher, Chairman of this Committee, for inviting the Office of Hawaiian Affairs to testify at this important hearing. I would like to take this opportunity to introduce our agency and discuss the plight of the native Hawaiians.

THE OFFICE OF HAWAIIAN AFFAIRS

The Office of Hawaiian Affairs is governed by an elected nine-member Board of Trustees. The trustees must be of native Hawaiian descent and are elected by eligible voters who must also be of native Hawaiian ancestry. As a result, the OHA trustees are directly accountable to their beneficiaries, the native Hawaiian people.

OHA was created in 1978 by an amendment to the Hawaii State Constitution. The basis for its establishment, however, dates back to our State Admission Act of 1959. The Act created a public land trust, the proceeds of which were to be used for five purposes. One of the purposes was the betterment of conditions for native Hawaiians.

In 1979 the State Legislature passed Act 196 which established the basic structure of OHA. This act, which was subsequently codified as Chapter 10, Hawaii Revised Statutes, set out the basic purposes, powers, duties and responsibilities of OHA. For your convenience, a copy of Chapter 10 is attached as Appendix A. Chapter 10 established OHA as the "principal public agency in this State responsible for the performance, development, and coordination of programs and activities relating to native Hawaiians." Chapter 10 also mandates OHA to serve as a receptacle for reparations and to act as a clearinghouse for federal or state assistance involving Hawaiian programs and projects. OHA is also responsible for advising, informing and coordinating federal, state and county activities relating to native Hawaiian programs. It is with this role in mind that OHA submits this testimony today.

THE PLIGHT OF THE HAWAIIANS

The poor social and economic condition of native Hawaiians is well documented in numerous studies, including Volumes I and II of the Native Hawaiians Study Commission Report, the Native Hawaiian Educational Assessment Project Report and E Ola Mau, the Native Hawaiian Health Needs Study. Volumes I and II of the Native Hawaiians Study Commission Report, which was mandated by Public Law 96-565, Title III, indicate that native Hawaiians suffer significantly higher unemployment than other residents of the State; higher rates of poverty and incarceration; the highest infant mortality; the lowest life expectancy; higher incidence of cancer and alcoholism; higher rates of respiratory conditions, such as asthma; higher rates of personality disorders and mental retardation; and higher suicide rates.

The Native Hawaiian Educational Assessment Project Report, initially authorized by Congress, but funded by a private organization, finds that native Hawaiians have the highest rate of academic and behavioral problems in schools; lower academic achievement; higher participation rates in social welfare programs; lower rates of enrollement in institutions of higher learning; and higher rates of truancy and dropouts than other ethnic groups in the State.

E Ola Mau, the Native Hawaiian Health Needs Study, funded by the U. S. Department of Health and Human Services, focused on mental health, medical, nutrition and dental problems of the native Hawaiian population. It also examined the historical and cultural context of native Hawaiian health needs. In terms of mental health, the study found that native Hawaiians have higher rates of social problems, including assaultive acts and antisocial behavior; alcohol and narcotics use; child abuse and neglect; and residence in correctional institutions. The medical section of the study confirm the findings of the two reports previously mentioned. In addition, it reports that native Hawaiians have higher rates of congenital abnormalities; underweight infants; chronic diseases such as diabetes, heart disease, hypertention and cancer; teen pregnancy; illegitimate births and inadequate prenatal care. The nutrition/dental section of the study found that the native Hawaiian diet was deficient in protein, phosphorous, iron, vitamins C and A and thiamine. In addition, native Hawaiians consumed too much fats, sugars and salt. The caries attack rate in Hawaii for permanent teeth among children 6-14 years of age is one of the highest in the nation, and native Hawaiian children had one of the highest DMF (decayed, missing and filled teeth) rates.

CONCLUSION

These statistics clearly show that all is not well in "paradise." Although our climate may be idyllic, the quality of life for native Hawaiians is not. Native Hawaiians, like other native Americans, have not been able to share in the good fortune of others in their state. For example, although reports show that people who live in Hawaii (as opposed to native Hawaiians) have the longest life expectancy in the nation, this statistic does not apply to native Hawaiians who comprise only 19% of the state population. The Office of Hawaiian Affairs strongly supports federal programs to help better the condition of all native Americans who face a myriad of social, physical and economic problems. It is our hope that you have a better appreciation for the plight of the native Hawaiians and that you are able to assist us in an effort to alleviate some of the problems that we face in common with other native Americans.

APPENDIX A

[CHAPTER 10]
OFFICE OF HAWAIIAN AFFAIRS

Section
[10-1] Declaration of purpose
[10-2] Definitions
[10-3] Purpose of the Office
[10-4] Office of Hawaiian Affairs; Established; General Powers
[10-5] Board of Trustees; Powers and Duties
[10-6] General Duties of the Board
[10-7] Board of Trustees
[10-8] Organization; Quorum; Meeting
[10-9] Compensation; Expense
[10-10] Administrator; Appointment, Tenure, Removal
[10-11] Salary of the Administrator
[10-12] Assistant; Staff
[10-13] Appropriations; Accounts; Reports
[10-13.5 Use of public land trust proceeds]
[10-14] Budget, Auditing
[10-15] Annual Report
[10-16] Suits

[§10-1] Declaration of purpose. (a) The people of the State of Hawaii and the United States of America as set forth and approved in the Admission Act, established a public trust which includes among other responsibilities, betterment of conditions for native Hawaiians. The people of the State of Hawaii reaffirmed their solemn trust obligation and responsibility to native Hawaiians and furthermore declared in the state constitution that there be an office of Hawaiian affairs to address the needs of the aboriginal class of people of Hawaii.

(b) It shall be the duty and responsibility of all state departments and instrumentalities of state government providing services and programs which affect native Hawaiians and Hawaiians to actively work toward the goals of this chapter and to cooperate with and assist wherever possible the office of Hawaiian affairs. [L 1979, c 196, pt of §2]

[§10-2] **Definitions.** In this chapter, if not inconsistent with the context:

(1) "Office" means the office of Hawaiian affairs;

(2) "Board" means the board of trustees;

(3) "Administrator" means the administrator of the office of Hawaiian affairs;

(4) "Native Hawaiian" means any descendant of not less than one-half part of the races inhabiting the Hawaiian Islands previous to 1778, as defined by the Hawaiian Homes Commission Act, 1920, as amended; provided that the term identically refers to the descendants of such blood quantum of such aboriginal peoples which exercised sovereignty and subsisted in the Hawaiian Islands in 1778 and which peoples thereafter continued to reside in Hawaii;

(5) "Hawaiian" means any descendant of the aboriginal peoples inhabiting the Hawaiian Islands which exercised sovereignty and subsisted in the Hawaiian Islands in 1778, and which peoples thereafter have continued to reside in Hawaii;

(6) "Beneficiary of the public trust entrusted upon the office" means native Hawaiians and Hawaiians. [L 1979, c 196, pt of §2]

[§10-3] **Purpose of the office.** The purposes of the office of Hawaiian affairs include:

(1) The betterment of conditions of native Hawaiians. A pro rata portion of all the funds derived from the public land trust shall be funded in an amount to be determined by the legislature for this purpose, and shall be held and used solely as a public trust for the betterment of the conditions of native Hawaiians. For the purpose of this chapter, the public land trust shall be all proceeds and income from the sale, lease, or other disposition of lands ceded to the United States by the Republic of Hawaii under the joint resolution of annexation, approved July 7, 1898 (30 Stat. 750), or acquired in exchange for lands so ceded, and conveyed to the State of Hawaii by virtue of section 5(b) of the Act of March 18, 1959 (73 Stat. 4, the Admissions Act), (excluding therefrom lands and all proceeds and income from the sale, lease, or disposition of lands defined as "available lands" by section 203 of the Hawaiian Homes Commission Act, 1920, as amended), and all proceeds and income from the sale, lease, or other disposition of lands retained by the United States under sections 5(c) and 5(d) of the Act of March 18, 1959, later conveyed to the State under section 5(e);

(2) The betterment of conditions of Hawaiians;

(3) Serving as the principal public agency in this State responsible for the performance, development, and coordination of programs and activities relating to native Hawaiians and Hawaiians; except that the Ha-

waiian Homes Commission Act, 1920, as amended, shall be administered by the Hawaiian homes commission;

(4) Assessing the policies and practices of other agencies impacting on native Hawaiians and Hawaiians, and conducting advocacy efforts for native Hawaiians and Hawaiians;

(5) Applying for, receiving, and disbursing, grants and donations from all sources for native Hawaiian and Hawaiian programs and services; and

(6) Serving as a receptacle for reparations. [L 1979, c 196, pt of §2]

[§10-4] Office of Hawaiian affairs; established; general powers. There shall be an office of Hawaiian affairs constituted as a body corporate which shall be a separate entity independent of the executive branch. The office, under the direction of the board of trustees, shall have the following general powers:

(1) To adopt, amend, and repeal by-laws governing the conduct of its business and the performance of the powers and duties granted to or imposed upon it by law;

(2) To acquire in any lawful manner any property, real, personal, or mixed, tangible or intangible, or any interest therein; to hold, maintain, use, and operate the same; and to sell, lease, or otherwise dispose of the same at such time, in such manner and to the extent necessary or appropriate to carry out its purpose;

(3) To determine the character of and the necessity for its obligations and expenditures, and the manner in which they shall be incurred, allowed, and paid, subject to provisions of law specifically applicable to the office of Hawaiian affairs;

(4) To enter into and perform such contracts, leases, cooperative agreements, or other transactions with any agency or instrumentality of the United States, or with the State, or with any political subdivision thereof, or with any person, firm, association, or corporation, as may be necessary in the conduct of its business and on such terms as it may deem appropriate;

(5) To execute, in accordance with its by-laws, all instruments necessary or appropriate in the exercise of any of its powers; and

(6) To take such actions as may be necessary or appropriate to carry out the powers conferred upon it by law. [L 1979, c 196, pt of §2]

[§10-5] Board of trustees; powers and duties. The board shall have the power in accordance with law to:

✓ (1) Manage, invest, and administer the proceeds from the sale or other disposition of lands, natural resources, minerals, and income derived from whatever sources for native Hawaiians and Hawaiians, including all income and proceeds from that pro rata portion of the trust referred to in section 10-3, of this chapter;

✓ (2) Exercise control over real and personal property set aside to the office by the State of Hawaii, the United States of America, or any private sources, and transferred to the office for native Hawaiians and Hawaiians;

(3) Collect, receive, deposit, withdraw, and invest money and property on behalf of the office;

(4) Formulate policy relating to the affairs of native Hawaiians and Hawaiians, provided that such policy shall not diminish or limit the

benefits of native Hawaiians under Article XII, section 4, of the state constitution;

(5) Otherwise act as a trustee as provided by law;

(6) Delegate to the administrator, its officers and employees such powers and duties as may be proper for the performance of the powers and duties vested in the board;

(7) Provide grants to public or private agencies for pilot projects, demonstrations, or both, where such projects or demonstrations fulfill criteria established by the board;

(8) Make available technical and financial assistance and advisory services to any agency or private organization for native Hawaiian and Hawaiian programs, and for other functions pertinent to the purposes of the office of Hawaiian affairs. Financial assistance may be rendered through contractual arrangements as may be agreed upon by the board and any such agency or organization; and

(9) Adopt and use a common seal by which all official acts shall be authenticated. [L 1979, c 196, pt of §2]

[§10-6] **General duties of the board.** (a) The general duties of the board shall be:

(1) To develop, implement, and continually update a comprehensive master plan for native Hawaiians and Hawaiians which shall include, but not be limited to, the following:
  (A) Compilation of basic demographic data on native Hawaiians and Hawaiians;
  (B) Identification of the physical, sociological, psychological, and economic needs of native Hawaiians and Hawaiians;
  (C) Establishment of immediate and long-range goals pursuant to programs and services for native Hawaiians and Hawaiians;
  (D) Establishment of priorities for program implementation and of alternatives for program implementation; and
  (E) Organization of administrative and program structure, including the use of facilities and personnel;

(2) To assist in the development of state and county agency plans for native Hawaiian and Hawaiian programs and services;

(3) To maintain an inventory of federal, state, county, and private programs and services for Hawaiians and native Hawaiians and act as a clearinghouse and referral agency;

(4) To advise and inform federal state, and county officials about native Hawaiian and Hawaiian programs, and coordinate federal, state, and county activities relating to native Hawaiians and Hawaiians;

(5) To conduct, encourage, and maintain research relating to native Hawaiians and Hawaiians;

(6) To develop and review models for comprehensive native Hawaiian and Hawaiian programs;

(7) To act as a clearinghouse for applications for federal or state assistance to carry out native Hawaiian or Hawaiian programs or projects;

(8) To apply for, accept and administer any federal funds made available or allotted under any federal act for native Hawaiians or Hawaiians; and

(9) To promote and assist the establishment of agencies to serve native Hawaiians and Hawaiians.

(b) The board shall have any powers which may be necessary for the full and effective performance and discharge of the duties imposed by this chapter, and which may be necessary to fully and completely effectuate the purposes of this chapter. [L 1979, c 196, pt of §2]

[§10-7] Board of trustees. The office of Hawaiian affairs shall be governed by a board to be officially known as the board of trustees, office of Hawaiian affairs. Members of the board shall be elected in accordance with chapter 13D, with reference to sections 11-15, 11-25, 12-5, [and] 12-6, and vacancies shall be filled in accordance with section 17-7. [L 1979, c 196, pt of §2]

Revision Note

Bracketed "and" was added.

[§10-8] Organization; quorum; meeting. The board, at its first meeting after an election, shall elect from its own membership a chairperson and a vice-chairperson who shall serve a term of two years. Their election shall be immediately certified by the board to the lieutenant governor.

A majority of all members to which the board is entitled shall constitute a quorum to do business. The concurrence of a majority of all members to which the board is entitled shall be necessary to make any action of the board valid; provided that due notice shall be given to all members.

Meetings shall be called and held at the call of the chair or by a quorum, as often as may be necessary for transaction of the board's business. The board shall meet at least once annually on each of the islands of Hawaii, Maui, Molokai, Lanai, Kauai, and Oahu. [L 1979, c 196, pt of §2]

[§10-9] Compensation; expense. Members of the board shall be allowed:

(1) Compensation at the rate of $50 a day for each day's actual attendance at meeting;

(2) Transportation fares between islands; and

(3) Personal expenses as provided under section 78-15 while attending board meetings on an island other than the island on which their residence is located.

All payments for compensation, travel, and expenses shall be paid by warrants signed by the chairperson of the board. [L 1979, c 196, pt of §2]

[§10-10] Administrator; appointment, tenure, removal. The board by a majority vote, shall appoint an administrator who shall serve without regard to the provisions of chapters 76 and 77 for a term to be determined by the board. The board, by a two-thirds vote of all members to which it is entitled, may remove the administrator for cause at any time. [L 1979, c 196, pt of §2]

[§10-11] Salary of the administrator. The salary of the administrator shall be $30,000. The administrator shall be included in any benefit program generally applicable to officers and employees of the State. [L 1979, c 196, pt of §2]

[§10-12] Assistant; staff. The administrator may employ and retain such officers and employees as may be necessary, subject to the approval of the board, to carry out the functions of the office. Such officers and employees may be hired without regard to chapters 76 and 77, and shall serve at the pleasure of the administrator. Officers and employees of the office of Hawaiian affairs shall be included in any benefit program generally applicable to officers and employees of the State. [L 1979, c 196, pt of §2]

[§10-13] Appropriations; accounts; reports. Moneys appropriated by the legislature for the office shall be payable by the director of finance, upon vouchers approved by the board, or by any officer elected or appointed by the board and authorized by the board to approve such vouchers on behalf of the board. All moneys received by or on behalf of the board shall be deposited with the director of finance and kept separate from moneys in the state treasury; except that any moneys received from the federal government or from private contributions shall be deposited and accounted for in accordance with conditions established by the agencies or persons from whom the moneys are received; and except that with the concurrence of the director of finance, moneys received from the federal government for research, training, and other related purposes of a transitory nature, and moneys in trust or revolving funds administered by the office, shall be deposited in depositories other than the state treasury. Income derived from the sale of goods or services and income from lands and property as described in section 10-3, shall be credited to special or other funds; provided that upon the recommendation of the office, the comptroller shall establish such other separate accounts or special funds for other designated revenues as may be directed by the board or its authorized representative. [L 1979, c 196, pt of §2]

✓**[§10-13.5 Use of public land trust proceeds.]** Twenty per cent of all funds derived from the public land trust, described in section 10-3, shall be expended by the office, as defined in section 10-2, for the purposes of this chapter. [L 1980, c 273, §1]

[§10-14] Budget, auditing. The board shall annually submit a proposed budget for the office to the legislature. The office shall be subject annually to government audit. [L 1979, c 196, pt of §2]

[§10-15] Annual report. The board shall prepare and make public their annual report which shall include an enumeration of their activities, income, and expenditures during the year. The annual report shall be submitted to the governor and the legislature ten days prior to the convening of each regular session of the legislature. The board shall prepare and submit special reports as may be required by the legislature. [L 1979, c 196, pt of §2]

[§10-16] Suits. (a) The office may sue and be sued in its corporate name. The State shall not be liable for any acts or omissions of the office, its officers, employees, and the members of the board of trustees, except as provided under subsection (b).

(b) In matters of tort, the office, its officers and employees, and the members of the board shall be subject to suit only in the manner provided for suits against the State under chapter 662.

(c) In matters of misapplication of funds and resources in breach of fiduciary duty, board members shall be subject to suit brought by any beneficiary of the public trust entrusted upon the office, either through the office of the attorney general or through private counsel.

(d) In matters involving other forms of remedies, the office, its officers and employees, and the members of the board shall be subject to suit as provided by any other provision of law and by the common law. [L 1979, c 196, pt of §2]

Severability, see L 1979, c 196, §11.

WEDNESDAY, APRIL 30, 1986.

NIH, ADAMHA

WITNESS

DR. DONALD R. KMETZ, DEAN, UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE, REPRESENTING THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

Mr. NATCHER. The next witness is Dr. Kmetz. Come around, Doctor. We are glad to have you before the committee. We will be pleased to hear from you.

Doctor, we are glad to hear you and we will listen to you.

Dr. KMETZ. Thank you, Mr. Chairman.

I am Donald Kmetz, Vice President for Hospital Affairs and Dean of the University of Louisville of Medicine. As a Kentuckian, I am particularly appreciative of this opportunity to appear before you today and to present the views of the Association of American Medical Colleges on fiscal year 1987 appropriations for the Departments of Health and Human Services and Education.

Mr. Chairman, before I begin, I would like to take a moment to reiterate our deep appreciation for your strong commitment to scientific research, education and, of course, health care. It is heartening to know that this subcommittee recognizes the need for effective biomedical research, quality patient care and, of course student financial assistance programs.

Our message today is really quite simple. The Federal Government must follow the policy that steady investment in research and education is an investment in our country's future. This policy should remain in place in spite of changes in the economy.

Somehow may must be found to keep America's unparalled research and education enterprise alive and responsive to the steady increasing momentum of discovery in the sciences. I can only highlight a few items for fiscal year 1987 appropriations bill.

More detail is included in the longer statement that I hope you will include in the record, as well as the proposal from the ad hoc group for medical research funding which we likewise would like to submit for the record.

Mr. Chairman, as you well know, knowledge is power. Just the short span of my personal experience in medicine there has been phenomenal growth in our power to deal with disease, a power directly transmittable to the new knowledge that is being accrued from wise past investments.

If I could just digress a moment with a personal experience. When I came to the University of Louisville in 1965—I am a pediatric hemotologist/oncologist—virtually 100 percent of our children with lukemia died. That is within my lifetime in the practice of medicine. Fifteen years later something in the range of upwards of 80 percent of the good risk patients in this age group with acute lukemia are long-term survivals, probably long-term cures.

Our hospital in Louisville together with some 30 or 40 institutions throughout the country, cooperated in a cancer cooperative study funded by NIH and I think there is no question that those kinds of studies, those and others throughout the country, really are directly responsible for that improvement in a dread disease transferring it from a fatal disorder to one that is really treatable.

I think that in one small sector of a person's experience makes the point that research must be continued. Despite our new knowledge based power, many intractable areas still remain where nature continues to hide their secrets from medicine's efforts to combat disease.

Of course, the disability and premature death associates and clearly the fact that we have two million people in this country with Alzheimer's disease, the fact that one out of three children born today will probably end up with cancer, the fact that we have some 60 million patients in this country with cardiovascular disease and there are perhaps two million children or so with mental deficiency problems, I think point to the fact that we still have horizons and research goals that have not yet been achieved.

In our view, the only hope for relief is through the steady funding of the best and most innovative research in good times and in bad. Research must be constantly nurtured but training the brightest young scientists, providing state of the art facilities and equipment and supplying the other necessary resources.

The ad hoc group for medical research funding, comprised of over 150 organizations of which the AAMC is one, has recommended that just over six billion be appropriated for the NIH and 465 million for ADAMHA research and training in fiscal year 1987 to provide modest real program growth.

This seems minimally responsive to scientific needs given the current economic climate. This would allow for the funding of approximately 33 percent of approved programs in contrast to the current funding base which supports about 37 percent of approved programs but, of course, much better than the anticipated 27 percent that would be associated with the proposed budget of 4.9 billion which, of course, is an eight percent decrease.

In the area of student assistance, the AAMC believes that financial aid is also an investment in America's future with benefits far exceeding the cost. The AMC has long held that students and/or their families should strive to pay for their own educations, however, few these days can shoulder this burden and most are forced to borrow.

Many, particularly those from socially, economically disadvantaged backgrounds, are not even applying to medical school because of the insurmountable debt upon graduation. About 87 percent of the students borrow money for their medical education and we find that the average indebtedness upon graduation is something in the range of $30,000.

There are very few who can bear that type of indebtedness without some assistance. It has been argued that the increased adequacies of physicians supply should relegate the health provisions education assistance to a lower priority.

We strongly disagree. Even medical school classes were cut in half to curtail physical supply. Federal scholarships and subsidized loans would still be critically needed so that the most worthy candidates could still attend medical school.

Regardless of their ability to pay, Title VII health provision training programs do not produce more doctors, but in our opinion they produce doctors more responsive and doctors more attuned to national needs.

These programs do encourage primary care. They encourage students to go, students and graduates to go into under-served areas to become involved in needed areas of geriatrics, which are specifically mandated and funded and we think they encourage cost effective care. For these reasons, the AAMC urges a current services budget for the student assistance and health manpower assistance programs under Title VII.

In the area of medicaid, the Administration has once again proposed to limit Federal matching payments at a time when 33 million Americans have no health insurance, another 17 million are under-insured and unemployment hovers at perhaps seven percent, the social beliefs that nothing short of full, Federal participation should be provided for the medicaid program.

Mr. Chairman, I place before you what the AAMC perceives as vital national needs. Supporting them should be viewed as an investment in America's future since today's down payments will yield untold benefits tomorrow.

We appreciate your dedication to these goals and trust that you will continue your wise assistance on the over-arching importance of research and of education.

Thank you, Mr. Chairman, for the opportunity to present these views.

[The statement of Dr. Kmetz follows:]

STATEMENT

OF THE

ASSOCIATION OF AMERICAN MEDICAL COLLEGES

on

FY 1987 Appropriations for the
Department of Health and Human Services
and the
Department of Education

The Association of American Medical Colleges (AAMC) appreciates this opportunity to submit its views on FY 1987 appropriations for the Department of Health and Human Services and the Department of Education. The Association represents the whole complex of individual organizations and institutions charged with the undergraduate and graduate education of physicians. It serves as the national voice for 127 accredited medical schools and their students; 435 major teaching hospitals and over 80 academic and professional societies whose members are engaged in teaching, biomedical and behavioral research, and patient care. All of these activities are directly affected by programs under the jurisdiction of the Labor-HHS-Education Appropriations Subcommittee. Exemplarily, almost 52 percent of the extramural investments of the NIH are in AAMC-constituent institutions.

Submitted to the House Appropriations Subcommittee on Labor-HHS-Education by the Association of American Medical Colleges, April 30, 1986.

aamc

Association of American Medical Colleges / One Dupont Circle, N.W. / Washington, D.C. 20036 / (202) 828-0525

Our message to this Subcommittee is quite simple: the federal government must be committed to the policies that continued investment in research and education is an investment in our country's future, and that our nation's poor and elderly should have access to quality health care, regardless of their ability to pay. These commitments should remain invariant, whatever the periodic and episodic fluctuations in the economy, lest short-term decisions driven by today's fiscal constraints have severe scientific, economic and societal repercussions tomorrow. Somehow, money must be found to keep America's unparalleled research and education enterprise alive and responsive to the steadily increasing momentum of discovery in the biological, behavioral and medical sciences, and to ensure that all citizens are able to obtain medical care.

The past four decades have witnessed a virtual revolution in the power of physicians to deal with the many diseases that afflict mankind, a power that is directly traceable to knowledge accrued from wise past investments that are paying off today. However, despite our new knowledge-based power, many intractable areas remain where nature presents medicine with tremendous challenges in its efforts to combat disease and disability. This country can and must meet the challenges posed by the 2 million elderly Americans afflicted with Alzheimer's disease; the 1 out of 3 babies destined to develop cancer in their lifetimes; the 60 million Americans with cardiovascular disease; the 3.5 million stroke victims; the 2 million children with mental disabilities so severe that they require constant care and attention; and countless other people with diseases too numerous to mention.

The Association believes that the only hope of meeting these challenges is through the steady funding of the best and most innovative research. By its very nature, research cannot be turned on and off; it must be constantly nurtured by taking on the brightest young scientists, providing state-of-the-art facilities and equipment, and supplying the necessary funding to make it all work. In this enterprise, the federal government plays a unique and vital role---by supporting the two federal crown jewels of research, the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). The ripple effects of continued investment in basic research conducted at these agencies are felt in many sectors of the economy, as advances developed through such research nurture the burgeoning biotechnology industry, help to reduce health care costs and contribute to deficit reduction. A strong research enterprise also positively affects employment, the foreign trade balance and industrial development.

The President's proposed FY 1987 funding levels for the NIH and ADAMHA are shocking. If enacted, the ability of these agencies to maintain America's preeminence in research would be seriously compromised and the hopes of millions of Americans who anxiously await new discoveries in biomedical and behavioral research would be dashed. At a time when funding should be increased to meet the increasing costs and complexities of conducting modern research, the Administration has proposed only $4.9 billion for NIH and $337 million for ADAMHA research and training in FY 1987, a substantial decrease (8 and 13 percent respectively) from the thoughtful and responsible levels appropriated by this Subcommittee for FY 1986.

Consider the impact of the President's budget on these research programs. The NIH's award rate for competing research project grants would fall from 37.2 percent in 1986 to a dismal 27.4 percent of approved applications, thereby signaling a substantial Federal retreat from support for research. Not only would these drastic reductions thwart the pursuit of new opportunities in the health sciences, but would seriously decrease the attractiveness of careers in health research. Many well-trained investigators with innovative ideas will be forced out of the research field and many bright young students will surely be discouraged from entering it, causing the pace of discovery in the coming years to slow measurably.

The Ad Hoc Group for Medical Research Funding, a coalition of over 150 organizations---including the AAMC---whose members are engaged in biomedical and behavioral research, has recommended that the NIH be funded at $6.076 billion and that the research and training programs of ADAMHA be funded at $465 million in FY 1987. The Association strongly supports these levels that would provide only very modest program growth over a current services level. The Association has heard no complaints that these recommendations are too high, and many that they are not high enough; nevertheless, they seem minimally responsive to scientific needs given the current economic climate.

The Ad Hoc Group's recommended levels would allow competing and noncompeting research project grants to be funded at study-section recommended levels, with a priority score cut-off of approximately 170 and an award rate close to 33 percent at NIH; comparable parameters at ADAMHA would be 175 and 48 percent, respectively. Even at these funding levels, however, over 12,000 worthwhile research grant applications at NIH would be unfundable. The Ad Hoc Group's recommendation would also: fund about 11,500 research trainees at NIH and 1,200 at ADAMHA, as recommended by the National Academy of Sciences; enable modest renovation and upgrading of outmoded and inefficient research laboratories in the seven national primate centers; stabilize funding for research centers to facilitate the conduct of clinical research projects and clinical trials; and maintain other essential programs at FY 1986 appropriations levels.

These recommendations reflect a concern with flexibility and program balance. The management of NIH and ADAMHA need budgetary flexibility and freedom to use their discretion if scarce federal research funds are to derive the "biggest bang for the buck." Determination of the optimal balance among investments in the conduct of basic and applied research, the training of qualified investigators, and the application of knowledge gained from these activities to the public is complex, highly technical and strongly influenced by the precise state-of-the-art in the program purview of each institute. The professional managers of the several national institutes with their extensive scientific advisory apparatus are in the best position to do this, provided sufficient flexibility is available to them.

In the area of student assistance, the AAMC has a long-held philosophy that students and/or their families should bear the primary responsibility for paying for their own educations. Realistically, however, few students or families can shoulder this burden out-of-pocket anymore, and most are forced to borrow up to 75 percent of their medical education costs. Indeed, many qualified college graduates, particularly those from socio-economically disadvantaged backgrounds, are not even applying to medical school because of the specter of insurmountable debt upon graduation. By 1985, the percentage of indebted students had risen to 87 percent with average indebtedness of $30,000. Even the Guaranteed Student Loan Program, which has been the cornerstone of medical school financing, has not kept pace with inflation. Although GSL loans have decreased by 25 percent in real terms since 1976, inflation-adjusted medical school tuitions since that time have literally skyrocketed by 113 percent for private schools and 95 percent for public schools.

As a matter of principle, schools of medicine strive to accept the most worthy candidates who apply for admission, regardless of their ability to pay. As a result, medical schools have increasingly sought to expand their own resources for student financial assistance, and the access of their applicants and enrollees to other aid sources. Medical school endowments now provide well over 10 percent of all student financial assistance, a large but still insufficient amount relative to the increasing costs of medical education.

In 1963, when the federal government adopted the public policy of increasing medical school enrollment to address the physician shortage, it promoted equality of access to medical education by providing scholarships, loans and loan guarantees. The Reagan Administration, however, has continuously argued that the increasing adequacy of the physician supply should relegate health professions educational assistance to a lower priority. The Association strongly disagrees with this policy: even if medical school classes were cut in half to curtail physician supply, federal scholarships and subsidized loans would still be critically needed to ensure that the most worthy applicants could matriculate, irrespective of their economic status.

The Association firmly believes that health professions training programs funded under Title VII of the Public Health Service Act do not produce more doctors, but doctors more responsive and attuned to national needs. These programs, which include Health Education Assistance Loans (HEAL), Health Professions Student Loans (HPSL), Exceptional Financial Need Scholarships (EFNS) and the National Health Service Corps (NHSC), promote greater access to medical education, encourage physicians to practice in underserved areas, and emphasize such national priorities as primary care, geriatrics and cost efficiency in the delivery of health care.

The Administration, however, has proposed major reductions in, or outright elimination of, many of these programs in FY 1987. The AAMC believes that at least a current services budget for health manpower and student assistance programs is necessary for FY 1987. We would also urge that the entire $290 million in HEAL credit authority for FY 1987 be made available to students, particularly since HEALs accounted for 18 percent of all medical school financing in the 1984-1985 academic year. We also recommend that the HPSL program, which has received no appropriation for the past 3 years be provided full funding. HPSL remains an extremely viable program that tenders badly needed low-interest loan capital to over 7,000 medical students each year.

Student financial aid is an investment in America's future, with the benefits far exceeding the costs. The currently staggering pace of scientific and technological advances in our world makes its obvious that the nation's only hope of meeting the demands of a modern society is to educate America's youth to their fullest potential. Short-term remedies to achieve modest "savings" in these programs will cost our country dearly in the long run, since the ability of the United States to compete in the industrial age depends on its success in training the next generation of scientific and technical talent.

For the Medicaid program, the Administration is once again proposing to limit Federal matching payments. At a time when 33 million Americans have no health insurance, another 17 million are underinsured, and the unemployment rate is hovering around 7 percent, the AAMC strongly believes that any reduction in Medicaid funding would be tantamount to completely turning our backs on the nation's poor and disadvantaged. Nothing short of full federal participation should be provided for these vital programs.

The Association regrets that time constraints do not permit us to speak to or enlarge upon other important health programs that serve sound public purposes and should be continued at reasonable levels --- the National Institute for Handicapped Research, the National Center for Health Services Research and Technology Assessment, the National Center for Health Statistics, and the National Institute for Occupational Safety and Health.

Mr. NATCHER. Dr. Kmetz, we want you to know, you made a good statement and we appreciate it.

WEDNESDAY, APRIL 30, 1986.

NATIONAL CANCER INSTITUTE

WITNESS

DR. ALBERT OWENS, AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Mr. NATCHER. Our next witness is Dr. Albert Owens. Come around, Dr. Owens, we are glad to have you back before the committee. The last shall be first. Doctor, we will be pleased to hear from you.

Dr. OWENS. Thank you very much. I am sure you are glad to see the last witness after a long day.

My job, as you may remember, being the Director of the Cancer Center at Johns Hopkins up in Baltimore, and why I am here today is to represent the American Society of Clinical Oncology, past President of that group, and presently Chairman of the Public Issues Committee, and our organization again is the largest of its type, and half are in practice taking care of cancer patients, and the other half are involved in research and teaching in our larger teaching institutions.

After coming here last year, we were very, very pleased with the strong statement that the Congress made in behalf of biomedical research, overriding the President's veto, and reauthorizing NIH and NCI, and I think we are back here because it seems that the NCI's budget which we are mostly concerned with, is less than it was in 1985.

We are very concerned that the Administration's recommendations for 1987 are even less. The impact of that, as we see it, is that about 27 percent of the approved research grants will be funded in that small a proportion.

There are centers where human research and applications are underway, that will be funded at about 25 percent of the recommended level, and four or five of them may in fact not be funded, which is a major departure from prior experience.

There are clinical trial groups, organ site programs budgeted 20, 25 percent less than prior years. Those are important because that is where a lot of the ideas meet the human needs that are trying to be fulfilled, and the futility and efficacy is examined.

The clinical education grants are cut by 50 percent. Funding for construction is eliminated, and I think even when you look at what ought to be our best cancer center, the National Cancer Institute, we find its personnel allotment, for example, is down 340-some over what it was in 1985, and we keep hearing that the budgetary process assigns NCI so many dollars in specific forms, that NCI is deprived of a lot of ability to move those funds around in response to scientific leads leads that open up, because of what you might refer to as micromanagement, we hear emanating from the Office of Management and Budget.

I think the thought I would like to leave is that in the past couple of years, we have focused a lot on research grants, and 6500, so on, on funding.

I would like to emphasize the fact that in order to put science in human service, there is a continuum that goes all the way from ideas to applications, and the research grants are important.

The clinical trials group is important, and some places to work, and self-renewal are important. It is a story that has to do with the chain being as strong as its weak link, and so I would like to not particularly see us single out a research grant number, but look very carefully at the entire continuum.

We would like to recommend that the NIH budget appropriation be at the nearly $6,100,000,000 figure that is put forward by the Ad Hoc Coalition for Biomedical Research.

I think we would very much like to see the NCI's appropriation match the $1,340,000,000 that was authorized by Congress last year, and I think those major recommendations are what all of the major organizations interested in the cancer problem have agreed are the major points they would like to make, sir.

I would like to just close by thanking you and your committee members for the leadership and the support you have provided in the past. I will express a concern which I am sure is not new to you. A lot of what we may not do in cancer research today, we won't feel the impact of for four, five, six years in the future, and it is not quite as dramatic.

I, one time, was sitting with a group of people like this, and someone got a little concerned that we were in here in times of financial stringency arguing for more funding.

We have the finest biomedical establishment in the world, and I could not think of anything better to say except that gosh, if we were having this conversation in 1960 about the automobile industry, or the steel industry in America, we would have said the same thing.

I just think we need to keep working on it, to keep it up there and to keep it doing what it is intended to do, putting knowledge into human service.

Mr. NATCHER. Thank you very much, Doctor. You have given an excellent statement. Thank you very much, Doctor.

[The statement of Dr. Owens follows:]

AMERICAN SOCIETY OF CLINICAL ONCOLOGY ASCO

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TESTIMONY OF

ALBERT H. OWENS, JR., M.D.

Director, Johns Hopkins Oncology Center
Baltimore, Maryland

In Behalf Of

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Concerning Fiscal Year 1987 Appropriations for

NATIONAL CANCER INSTITUTE

HOUSE SUBCOMMITTEE ON LABOR-HHS-EDUCATION APPROPRIATIONS

APRIL 30, 1986

1986 Annual Meeting May 4-6, Los Angeles, CA

Mr. Chairman, I am Albert H. Owens, Jr., M.D., Director of the Johns Hopkins Oncology Center in Baltimore, Maryland. Also, I serve there as Professor of Oncology and Professor of Medicine.

Today I appear before you on behalf of the American Society of Clinical Oncology (ASCO). I am Chairman of the Public Issues Committee and a former President of ASCO.

Although I am sure that you will recall information about our organization, I would like to supply some of it for the record, to place our concerns in perspective regarding the fiscal year 1987 proposal for the NCI budget by the Administration.

The American Society of Clinical Oncology was founded 20 years ago and has become the nation's largest organization of specialists involved in providing cancer patient care, conducting clinical cancer research and training cancer physican specialists. Members of this Society are involved directly, or as consultants, in the care of the majority of the cancer patients in the United States. Its members include the nation's leading physicians in medical oncology, pediatric oncology, radiation oncology, surgical oncology, gynecologic oncology, and also basic scientists in pathology, immunology, pharmacology, biostatistics, and other areas of basic biomedical science. Collectively, this Society represents the nation's major resource of specialists in the diagnosis and treatment of cancer patients, the application of research to cancer patients and the training of the cancer physicians and clinical researchers of the future. Approximately half of its members are practicing physicians caring for the nation's cancer patients in their offices and in many community hospitals, and half are engaged in research and training in literally all of the nation's schools of medicine, cancer hospitals, centers and institutes.

OVERALL VIEW

Last year the Congress made a very strong statement in support of biomedical research at a time when it was also facing severe budgetary problems. Mr. Chairman, we appreciate your hard work to create a major increase in funding for the National Cancer Institute; the ensuing appropriations bill was an excellent one. In addition, when the Congress overrode the President's veto of the NIH authorization bill, it set very reasonable appropriation authorizations for cancer research at $1.34 billion.

Despite an unambiguous Congressional mandate, the funding made available to the National Cancer Institute in 1986 was substantially below the 1985 level. Further, the Administration's proposed budget for fiscal year 1987 will reduce it even further.

Fortunately, the cancer research enterprise in this country is burgeoning with discoveries of great potential benefit to the American people. Cancer research, by its nature, is a continuum which extends from ideas to application. This process is no stronger than its weakest link. Further, we would observe that the matter of reducing science to human service is highly dependent on the work of well-educated and extraordinarily dedicated people.

The 1986 funding of the NCI severely threatens the effectiveness of the cancer research continuum:

- Only 27% of approved research grants are funded
- Centers are funded at 25% below approved levels and the funding of 5 center grants is expected to terminate
- Clinical trials groups and organ site programs are budgeted at 20% of last year's levels and some groups are terminated

- Clinical Education grants are reduced by 50%; other research training by 10% or more
- Construction grants are eliminated
- The intramural NCI program is severely constrained; e.g., its present personnel positions are being held at 344 below 1985 levels.

If the Administration's proposed budget for 1987 is adopted, the situation will worsen to the point of devastation. Without adequate federal funding the cancer research enterprise cannot continue to be effective in meeting one of the nation's major health problems. For example, without adequate funding, sufficient cancer research grants will not be available to explore our best ideas and without appropriate funding for cancer centers and clinical trials groups, human disease research and treatment applications will be even more severely limited.

RECOMMENDATIONS

In brief, Mr. Chairman, ASCO would like to advance the following recommendations:

1. We support the Ad Hoc Coalition for Biomedical Research's funding level of $6.073 billion for the NIH.

2. We believe that last year's Congressional authorization for the NCI appropriation of $1.34 billion is most reasonable for an FY 1987 appropriation level.

3. We believe that it is imperative to maintain the effectiveness of this country's cancer research enterprise by restoring the funding of research grants, centers, clinical trials groups, etc., to peer review approved levels, and to assure appropriate growth for those areas of research.

I believe that you will find all of the major organizations concerned with cancer research and treatment are in accord with these main points.

APPRECIATION

Mr. Chairman, please accept our heartfelt thanks for your continued support and know that we appreciate your courtesy in hearing us again this year.

Mr. **Natcher**. The committee will now adjourn until 11:00 in the morning.

THURSDAY, MAY 1, 1986.

NIH RESEARCH FOR SKIN DISORDER

WITNESS

DR. PEYTON E. WEARY, AMERICAN ACADEMY OF DERMATOLOGY

Mr. NATCHER. Our first witness this morning is Dr. Peyton Weary. It is a pleasure to have you back before the committee again, and we will be pleased to hear from you.

Dr. WEARY. It is a real pleasure for me to be here today, Mr. Chairman, because this represents a new beginning for us. We are so pleased that we have a new Institute of Arthritis, Musculoskeletal and Skin Diseases, and the amount of excitement in the research community is extraordinary as a result of this.

We think that it is essential that this new Institute be supported in an appropriate way, because it is a fledgling Institute, and it needs to get off on the right start.

We feel that, to provide adequate support for this new Institute, would be in consonance with the wishes of the Congress who so vigorously supported the creation of this new Institute, and we urge that it be supported well.

We think that the scientific opportunities have never been greater than they are right now in regard to skin disease. I am going to pass out to you, if I may, some press releases which I obtained this morning.

The Society for Investigative Dermatology is meeting at the present time here in Washington, and I obtained these press releases and thought you might be interested in seeing these.

These are nine different presentations that we made at this meeting in regard to new advances in research in skin diseases, and all of these have been supported in one way or another by the monies that have been appropriated by this subcommittee and the Congress, and we think you should be justifiably proud of these advances.

We support the Coalition budget of $151,650,000. We think this would establish pay lines of 170, in contrast to the projected pay lines of 150, which are under the President's proposed budget.

We also believe this could provide an award rate of 34 percent in contrast to the projected 24 percent award rate under the President's proposed budget.

We have heard previously that if the President's proposed budget is accepted, there would be a need to cut the grant support for the new Institute by as much as 16 to 18 percent across the board.

This is in contrast to the projected current cut of about 11 percent for fiscal year 1986.

Now, Mr. Chairman, there are no good data which clearly show what the impact of these across-the-board cuts are, but we think that they may be significantly counterproductive in the long run, and we feel that further cuts of the magnitude that would occur under the President's proposed budget would be quite detrimental.

We also note that the efforts of the Office of Management and Budget to impose arbitrary ceilings on indirect research cost reimbursement and feel that this two-pronged assault on biomedical research funding may prove to be very detrimental in the long run.

We have been told furthermore, under the President's proposed budget, the number of new grants will be reduced from a projected number of 199 in 1986 to only 148 in 1987, and that the existing grants will fall from approximately 582 to 573.

We think this is most disturbing and clearly in conflict with the Congressional intent to stimulate more and not less research, in diseases which will come under the purview of the new Institute, so we urge that the subcommittee give serious consideration to the proposed figure that the Coalition has come up with of $151,650,000.

We think also that in this budget, there is support for six centers for research in dermatologic diseases, and we think these centers will be important for us in providing the proper training for new researchers as well as conducting good research in skin disease.

While I am here also, I would not like to neglect the funding for other Institutes for which we have spoken in the past. The intramural program at the NIH and in dermatology is in the NCI, and has been one of the shining stars in the dermatologic research effort.

It is a training ground for many of the very able researchers coming out now, and we think that that must be supported well, too.

Also, Mr. Chairman, we have great concern about the support for the Institute for Occupational Safety and Health, and feel that this has been an underfunded Institute, and it is not part of the NIH, but nevertheless, it deserves support.

We have emphasized the fact that there is a large amount of occupational skin disease which accounts for a significant burden of lost time, productivity in agriculture and in industry, and this type of skin disease is something that needs to be looked into very much by the National Institute for Occupational Safety and Health, and would urge increased support for that Institute.

I thank you for the opportunity to present this testimony.

Mr. Natcher. Thank you very much, Dr. Weary. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Dr. Weary follows:]

TESTIMONY OF

Peyton E. Weary, M.D.

On Behalf of

The American Academy of Dermatology, Inc.

and

The Society for Investigative Dermatology

Regarding FY 1987 Appropriations

for

The National Institute of Arthritis and Musculoskeletal and Skin Diseases

The National Institute of Allergy and Infectious Diseases

The National Cancer Institute

The National Institute on Aging

The National Institute of Environmental Health Sciences

and

The National Institute for Occupational Safety and Health

Before the Subcommittee on Labor, Health and Human Services,

Education and Related Agencies

United States House of Representatives

May 1, 1986

Mr. Chairman, I am Peyton E. Weary, M.D., Professor and Chairman of the Department of Dermatology at the University of Virginia School of Medicine and Washington Representative from the Council on Governmental Liaison of the American Academy of Dermatology. I am also the immediate past Vice-President of the Society for Investigative Dermatology. I am presenting this testimony on behalf of the American Academy of Dermatology, whose membership of over 6,500 represents the majority of American Dermatologists, and on behalf of The Society for Investigative Dermatology, the representative organization for the dermatologic biomedical research community.

I am delighted that, after more than ten years of testifying before this Subcommittee, I have the honor, this year, to testify in support of a new institute, The National Institute of Arthritis and Musculoskeletal and Skin Diseases which represents the culmination of a dream for many of us. We applaud the determination of the Congress to create this new institute in recognition of the contribution of a large number of disabling and disfiguring chronic diseases to the burden of illness in our society. In calculating the socioeconomic impact of these diseases, it is important to bear in mind that it is estimated that approximately 60 million Americans will have a significant skin disease during their lifetime and the estimated annual combined direct and indirect cost of skin disease is 6.8 billion dollars. The challenge now for all of us is to make this new institute the best and most productive it can be and the dermatologic organizations pledge our support for this effort.

Mr. Chairman, we feel it is essential in any new venture to assure that the financial base is adequate and secure and, it is for this reason, that our organizations support the recommendations for funding in the amount of

$151,650,000 prepared by the coalition of organizations concerned with programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases for FY 1987. We believe that scientific opportunities are clearly identified which would justify the level of support suggested. You will note that the coalition's recommendations call for additional funds in the amount of 2.4 million dollars to support six core centers in dermatology and we strongly endorse this new initiative in the belief that it will provide significant new opportunities to capitalize upon the recent advances being made in a number of important areas of dermatologic research. Among the frontier areas of dermatologic research, I would direct your attention particularly to the following:

1. There are significant new advances in understanding several of the blistering diseases such as Epidermolysis Bullosa and Pemphigus as outlined for you earlier by Dr. Shulman in his testimony.
2. The use of cultured skin cells as a mechanism for grafting burns, ulcers and denuded skin suggests exciting new horizons for research.
3. A family of compounds derived from Vitamin A called retinoids has revolutionized the treatment for severe acne and holds great promise for a number of other disabling diseases such as psoriasis.
4. The discipline of photobiology which studies the effects of visible light and ultraviolet radiation upon the skin is expanding rapidly, and ultraviolet light is even being used on an experimental basis by dermatologists to kill malignant cells in the blood through a process called photophoresis.
5. There are inherited disorders in which the horny layer of the skin thickens and which are called, as a group, ichthyosis. As science continues to unlock basic aspects of disease more and more of such

inveterate diseases yield to new therapeutic efforts.

I would emphasize that these are only some of the exciting new opportunities which have been generated by previous NIH support and await your continued support through the provision of adequate funds for the research activities in the new institute.

Mr. Chairman, we support the recommendations for overall N.I.H. support of the Ad Hoc coalition for biomedical research. We also wish to express our continuing concern about funding levels for several other institutes at the NIH (NCI, NIA, NIAID, NIEHS) and for the National Institute for Occupational Safety and Health. All of these institutes support important research in skin disease and, in particular, we direct your attention to the superb intramural program in dermatology research which is located in the NCI. With the increased incidence of skin cancer and, in particular, malignant melanoma, support of research on cancer of the skin is most appropriate. This research provides an important adjunct to the efforts of dermatologists to detect and prevent skin cancer and, in particular, malignant melanoma through the more than 400 skin cancer detection and prevention clinics held last year. This year our efforts at skin cancer detection and prevention will be expanded and targeted particularly to elderly Americans.

We continue to have concern about the levels of funding for the National Institute for Occupational Safety and Health. Previous funds are not adequate to support much needed research in occupational skin disease which causes such a significant economic loss to this country's productivity.

Thank you for the opportunity to express our views and also our appreciation to the Congress for their continued support of the NIH. Next year the NIH will have its centennial celebration. I for one believe this should represent a celebration of a most enduring and rewarding partnership between the NIH, the Congress and the administration, for without each of these three working for the advancement of medical science, the preeminence of the NIH would not have been possible. So we applaud you for your role in this partnership and hope for your continuing leadership in improving the health care of the nation through research.

COALITION OF ORGANIZATIONS
Concerned with the Programs of the
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

Statement for the
Subcommittees on Labor, HHS, and Education
Committees on Appropriations
United States Senate
and
United States House of Representatives
with respect to the
FY 1987 Budget of the
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
National Institutes of Health

Introduction

The Coalition of Organizations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is pleased to have this opportunity to submit its joint statement on FY 1987 appropriations for the newest NIH research institute. The 30 organizations supporting this statement want to insure that the new NIH Institute is properly established as a fully functioning research institute at the earliest possible time.

The members of this Subcommittee are aware that NIAMS was established in law on November 20, 1985. Fiscal Year 1987 marks the first opportunity for Congress to address research needs of the programs encompassed by this new Institute as a separate budget line item.

The President has supported the creation of NIAMS, and the Congress has endorsed it through several nearly unanimous votes. We now urge you to appropriate funds for the new Institute at a level adequate to allow it to initiate the focussed, national research program contemplated by Congress at the time of its establishment.

Research Needs

Arthritis, rheumatic, and related musculoskeletal and connective tissue diseases, comprise over 100 distinct forms, affecting more than 38 million Americans, including as many as 250,000 children. The better known of these conditions are osteoarthritis, rheumatoid arthritis, gout, scleroderma, lupus erythematosus (SLE, or lupus), and ankylosing spondylitis, or spinal arthritis. Many millions more of our people have osteoporosis, osteogenesis imperfecta, Paget's disease of bone, pemphigus, ichthyosis, neurofibromatosis, tuberous sclerosis, alopecia areata, psoriasis, epidermolysis bullosa, Marfan's syndrome, vitiligo, melanoma, skin cancer, and other diseases of the bone and skin. In addition, there are many healthy Americans whose musculoskeletal systems are disabled by falls, fractures, motor vehicle accidents, and sports-related injuries.

All these serious diseases or conditions result in morbidity, mortality, and disability, which cost the American economy many billions of dollars each year in medical care, lost wages and productivity, lost taxes, increased disability and workers compensation payments, and increased social services costs. Research advances in the past decade have brought about improved treatment, control of disease, better diagnostic methods, and important new surgical procedures which strongly indicate that accelerated and targeted research efforts can sharply ameliorate, control, prevent, and cure a number of these diseases. This promise was a major reason for the creation of the new Institute. Now Congress and the President must give our Nation's scientists the means by which to fulfill the promise.

Biomedical research, and more specifically research to improve the lives of as many as 50 million Americans with arthritis, bone, and skin diseases, should be one of the highest of this Nation's priorities. The loss of momentum in biomedical research through reduced or level funding would mean a serious loss of research opportunity for many years to come and the real potential exists for the loss of an entire generation of investigators.

Funding Recommendations

Attached to this statement is a table showing funding necessary to maintain research efforts at current services levels, and the Coalition's recommendations for NIAMS appropriations for FY 1987.

The recommended support level for investigator-initiated research grants (RO-1) would fund 223 new grants in FY 1987, and a total of 612 new and continuation grants. At this level, the estimated award rate for new grants would be 34%, with a priority score payline of 170. The $100 million we urge is only 3% greater than the current services level.

Although the Coalition recommends funding at current service levels for training and contracts, we urge initial funding of Specialized Centers of Research (SCORs) to target multidisciplinary research approaches in three areas: osteoporosis, osteoarthritis, and rheumatoid arthritis, as both House and Senate Appropriations Committees recommended last year. We also request an increase of $2.4 million over current services in Centers funding to support six core centers in dermatology.

The "other research" category includes Clinical Investigator and Physician Scientist awards, both of which must have reasonable funding if our research community is to remain viable in future years. No new awards would be possible under the President's FY 1987 budget. Intramural research must be strengthened to complement extramural activity.

Institute Staffing

At current personnel levels, NIAMS cannot function as an independent Institute. Under the NIH organization plan, the Arthritis and Rheumatism Branch and Laboratory of Physical Chemistry in the NIADDK intramural program are transferred to NIAMS (35 positions), along with 14 extramural personnel. When the administrative separation from NIADDK takes place, an additional 8 slots are scheduled to be assigned to NIAMS. In order to be minimally effective as a working Institute, NIAMS requires another 36 personnel. Under the President's FY 1987 budget, $1 million additional is provided (but no positions) in the RMS (research management and support) activity. If positions are made available, this additional amount will permit the placement of 15 to 20 staff. Another $1.5 million is necessary to provide the minimum of 36 additional personnel.

Conclusion

The Coalition believes that the amounts it is recommending for FY 1987 are fiscally sound and minimally adequate to make NIAMS operational and effective as an NIH research institute. There is substantial scientific justification for the higher FY 1987 budget proposed by the National Arthritis Advisory Board. If the Congress determines these levels to be attainable this year, the Coalition would most certainly support them. At a minimum, however, we urge Congress to enact, and the President to approve, appropriations for FY 1987 at the level the Coalition recommends, to firmly establish NIAMS and to begin the level of research effort essential to finding the answers to the diseases addressed by the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

LIST OF ORGANIZATIONS
ENDORSING STATEMENT ON FY 1987 APPROPRIATIONS

Coalition of Organizations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases

American Academy of Dermatology
American Academy of Orthopaedic Surgeons
American Academy of Physical Medicine and Rehabilitation
American Brittle Bone Society
American Congress of Rehabilitation Medicine
American Lupus Society
American Juvenile Arthritis Organization
American Rheumatism Association
American Society for Bone and Mineral Research
Arthritis Foundation
Arthritis Health Professions Association
Dystrophic Epidermolysis Bullosa Research Association
Federation of American Societies for Experimental Biology
Helen Hayes Hospital
Lupus Foundation of America
National Alopecia Areata Foundation
National Foundation for Ectodermal Dysplasias
National Ichthyosis Foundation
National Marfan's Foundation
National Osteoporosis Foundation
National Psoriasis Foundation, Inc.
Orthopedic Research Society
Osteogenesis Imperfecta Foundation, Inc.
Rehabilitation Institute of Chicago
Society for Investigative Dermatology
Terri Gotthelf Lupus Research Foundation
The Dermatology Foundation
The National Neurofibromatosis Foundation, Inc.
The National Tuberous Sclerosis Foundation
The Paget's Disease Foundation, Inc.
United Scleroderma Foundation

NIAMS

(Dollars in thousands)

	1985 Actual		1986 Appropriation plus Carryover		1987 President's Budget		Current Services		1987 Coalition Proposal
Grants	190 565	$77,554	199 582	$83,599	148 537	$75,011	199 588	$96,712	$100,000
Centers	14	10,064	14	10,231	14	9,317	14	11,909	14,309
Other	67	4,814	63	5,087	56	4,868	63	5,087	7,800
Training	233	6,130	268	6,130	257	5,867	268	6,130	6,130
Contracts	7	2,013	7	2,848	6	2,536	7	3,018	3,018
Intramural Res.		6,478		6,467		6,181		7,141	8,000 4,743
RMS	49	1,755	49	2,136	48	2,953	49	3,243	7,650*
Totals		108,808		116,498		106,733		133,240	151,650

*New Item - Specialized Centers of Research (SCORs).

THURSDAY, MAY 1, 1986.

EPIDERMOLYSIS BULLOSA

WITNESSES

ARLENE PESSAR, EXECUTIVE DIRECTOR, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

RAY CALDWELL

MRS. CALDWELL

ESTELLE LARSON

Mr. NATCHER. Mrs. Pessar, you come around. I believe you have with you Ray Caldwell, and Mrs. Caldwell, and Mrs. Larson. You all have a seat now, and we will be pleased to hear from you.

Mrs. PESSAR. Thank you. It is wonderful to be back.

It is a great honor that we can be here. This past year has been filled with excitement and unprecedented opportunity in epidermolysis bullosa, and it is because of your concern, compassion and commitment to expand research on this terrible disease that has made this extraordinary progress possible.

On behalf of the thousands of EB patients and families all over the country, and the world, who suffer from this group of severe blistering skin diseases, I would like to express my deep gratitude and appreciation to you and the members of the subcommittee for your strong support of this intensified effort.

This year, I am accompanied by Ray Caldwell and his mother, and Estelle Larson, who you have met before.

Ray is six years old and suffers from a form of EB, commonly referred to as EB letalis (EB junctional), because most children born with this form of EB usually die in infancy; or, if they survive, lead very restricted lives.

We think of Ray as a "miracle child" because he has defied the odds. Each of you, and your colleagues in the Congress, past and present, can, and should, take credit for this miracle.

Ray is here with us today and living a normal life because of your long-standing commitment to the NIH and its research programs.

During the past year, Ray has been treated by Dr. D. Martin Carter and his associates at the Rockefeller University, New York City, using a therapy that was pioneered by NIH grantees at the Massachusetts Institute of Technology and Harvard in the 1970s to help patients with severe skin ulcers and burns.

Ray was born with large areas of skin missing on his face and body. These areas of denuded were severely painful and disfiguring. Because of the potential for metabolic imbalance and susceptibility to infection, they were also life-threatening.

In spite of intense therapy at several medical centers throughout his life, little could be offered to help Ray.

During the past year, these raw areas were treated with skin grafts consisting of cells obtained from Ray's own skin and grown into sheets in the laboratory. After repeated grafting, Ray's facial skin is now completely normal except for some loss of pigment.

But even this is now returning, and will continue to improve with time. With healing of his facial skin, it became possible for Ray to undergo surgery to correct abnormalities of this eyelids and nose caused by EB. Now for the first time in his life, Ray is facing the world with skin instead of raw open patches on his face.

This procedure has been successfully used on three patients with EB junctional. Additional research is needed to determine if this therapy can be used for the ED population at large.

The General Clinical Research Centers provide the kind of specialized environments required to study and treat complex human diseases like EB. We urge you to continue to vigorously support the vital and outstanding programs funded under the auspices of the Division of Research Resources.

In addition to the work being done at the Rockefeller University, I would like to update you on some of the other progress that has been made during the past year in EB.

In accordance with this committee's directives and wishes to intensify research on EB, the National Institute of Arthritis, Musculoskeletal and Skin Diseases has dramatically increased its initiatives to stimulate more research.

As a result of a solicitation on EB and the biology of the basement membrane zone, 10 new grants were funded. We are optimistic that these basic research grants will bring promising new findings which will one day improve the quality of life for all who suffer from EB and other serious diseases of the skin.

One of these new grants is to support a conference on the nondermatologic complications of EB. Although a great deal has been learned about the basic biochemical and structural integrity of the skin, virtually little is known about lesions affecting internal organs, such as the eyes, mouth, esophagus, gastrointestinal, respiratory and urinary tracts.

Chronic blistering and scarring in these organs often result in painful medical complications, disability and early death.

By addressing the state of the current understanding of EB, we hope to pull together critical information that until now was anecdotal in nature. This should also help to focus on new avenues for research and treatment.

In addition, this year the Institute will be supporting a national EB registry. The registry will serve to increase information on the genetics of EB, improve methods of diagnosis and prenatal diagnosis, and develop new therapeutic modalities for the different types of EB.

To build and consolidate on all this recent success and take advantage of the great potential for major research advances, we urge the subcommittee to continue its commitment and give high priority to research relevant to EB in its final report to the Congress.

Today, we at DEBRA, along with the other members of this Coalition, are here as advocates. The establishment of a new National Institute of Arthritis, Musculoskeletal and Skin Diseases provides an extraordinary opportunity to address the health needs of millions of people who are victims of the serious and debilitating diseases funded under this Institute.

We are hopeful that even in these stringent economic times, this committee will continue to exercise its wise and caring judgment and appropriate the funds necessary to establish this Institute as a fully functioning research entity.

We fully support and endorse the Coalition's budget recommendations and urge you to approve a funding level of at least $151,650,000 in fiscal year 1987 for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

Included in this budget recommendation is $2,400,000 to support six core centers in dermatology. Today, the state of science in dermatology, generally, and EB specifically, is at a point that would greatly benefit from the concentrated interdisciplinary effort that bring clinical and basic research capabilities together.

We strongly endorse this $2,400,000 recommendation and urge you to appropriate these funds to develop these six centers. We also hope this committee will recommend that, at least, one of these dermatology centers be developed with a strong research emphasis that relates to EB.

Mr. Chairman, I believe one day there will be a cure for many of these tragic diseases. It might not be this year, but with your continued commitment and support, I know we will see it in our lifetime.

Thank you for your compassion and concern. Your support has made a difference. I urge you to continue to make a difference. I believe Estelle has regards from her son.

Mrs. LARSON. I am here to bring a message from my son. Five years ago, when we went to offices, the offices of each committee member, to show what the children of that time could expect to grow up to be, he did so hoping that you would respond with funding for the disease.

You responded with language, and with funding, and out of this, we have seen some results this year. The awareness of other researchers, and applying it to some of the basic research that has already been done, and Cal sends a message of gratitude that you were responsive.

I thank you.

Mr. NATCHER. Thank you very much, and we appreciate you coming before the committee this morning. Mrs. Pessar, you have made an excellent statement. We appreciate your appearance before the committee.

I say this to you, the same as we have said to a number of people that have appeared before the committee during the past 12, 14 weeks, we can't accept the budget requests that have been sent to us. There are some people here in this room that had a lot of experience with committees on the other side and on this side that know that last year, we had a similar situation.

I did not accept the requests. We have told them downtown we can't accept them. Mrs. Pessar, we are going to bring out a good bill. You take my word for that. It is going to be a good bill. You are going to like it.

Ray, I appreciate your coming. Don't you leave now, because I got a little book I want to give you.

You hang in there now, Ray. Good luck to you.

THURSDAY, MAY 1, 1986.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

WITNESSES

SUSAN NYE DeHAAN, PRESIDENT, NATIONAL ICHTHYOSIS FOUNDATION
SARAH MASSEY
ROBERT MASSEY

Mr. NATCHER. Our next witness is Mrs. DeHaan. Come around, Mrs. DeHaan.

Ms. DEHAAN. The National Ichthyosis Foundation is pleased to be here this morning.

I don't believe you have heard from us before. The Foundation is a new organization that emerged about five years ago to provide support for individuals suffering from ichthyosis, and I have Robert Massey, 15 years old from Fountain Inn, South Carolina, and his mother, Sarah.

Robert has epidermolytic hyperkeratosis. He acquires blistering along with the scales.

Ichthyosis is a genetic disorder. There are four types that have been identified.

Depending on the type the person has, they have different types of symptoms. In some cases, people are born with large brownish-black scales that are all over their body. The outer layer of the skin is very hard, and the skin does not operate properly, doesn't shed, so the scales remain on the body, a very disfiguring kind of condition.

In some cases, people have larger white scales all over their body. There are other kinds of things that go along with ichthyosis, increased number of still births, retardation, hearing loss, eye problems, and complete hair loss.

Often, our kids who have ichthyosis suffer from the itching and bleeding, and high temperatures that they get, because they have to remain in an ideal kind of environment. If the temperature goes up outside, 80 degrees, their body temperature will increase to 100, 102, 104 degrees and result in brain damage, and critical condition, because they do not perspire.

The majority of the parents' time, particularly with the very young child, is spent in trying to keep the skin soft, so that the child can move. We have a lot of children that are wheelchair-bound and are not able to ambulate because the skin is so tight, they have no motion.

Along with this devastating physical kind of conditions, they have psychological ones. You can imagine how it is for someone to go about in society with this disfiguring appearance.

People are not used to seeing it, I suppose many of you are not familiar with this at all. Individuals just become isolated, reclusive and don't go out of their homes because of the kind of social experiences they have.

We estimate that one in every 100,000 people have some type of ichthyosis, probably about 5,000 severe cases, but we really don't know. It is a rare disease, and often appears spontaneously in families where there is no history, so parents are at a loss as to what to do when the child is born.

They often go from doctor to doctor, and being a rare disease, physicians are often not experienced with it, and getting a diagnosis is difficult.

People actually believe—sometimes they have never seen another person and they live in isolation, so we are hoping that with the support of Congress, that we may be able to get some research funds to find the causes of this disease, so it will be eradicated.

We have 7500 people in the Foundation that we reach, and this is really too small a number for these folks to be able to raise the kind of funds it will take to find the cause and eradicate, so we are urging, along with the other members of the Coalition, that you would adopt a budget that will get the new Institute off to a good start, so its programs will be realized.

I have been involved myself, because I am a psychiatric social worker and handled a patient seven years old who was referred to me for counseling, because she was quite withdrawn, almost psychotic because of the school experiences she was having with the disease, and the itching was driving her crazy, and they were concerned about giving her itching medication because of its neurological effects of that.

I felt that there was nothing I was going to be able to do for her, so I saw one of the research doctors on TV who receives funds out of NIH on TV with one of her patients and got these people together, and that is how we started the Foundation.

I know the money is well spent through NIH grants. I have brought some pictures, if you would like to see?

Mr. NATCHER. Thank you very much.

[The statement of Ms. DeHaan follows:]

NATIONAL ICHTHYOSIS FOUNDATION
A NON PROFIT CORPORATION

NATIONAL ICHTHYOSIS FOUNDATION
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Subject: FY 1987 Budget of NIAMS, NIH

Date and Time: Thursday, May 1, 1986, 11:10 a.m.

A NON PROFIT CORPORATION

NATIONAL ICHTHYOSIS FOUNDATION

P.O. Box 252 Belmont, Ca 94002 Phone (415) 591-1653

Statement of the
NATIONAL ICHTHYOSIS FOUNDATION
Concerned with the Programs of the
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

Before the
Subcommittee on Labor, HHS, and Education
Committee on Appropriations
U.S. House of Representatives
with respect to the
FY 1987 Budget of NIAMS, NIH

May 1, 1986, 11:10 a.m.

INTRODUCTION

The National Ichthyosis Foundation as a member of the coalition of organizations concerned with the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, is pleased to have this opportunity to submit its statement regarding FY 1987 Appropriations for this new NIH research institute. We are especially concerned with funding for NIAMS in FY 1987 as this is the first opportunity for Congress to address the research needs of the programs encompassed by this new institute. The National Ichthyosis Foundation and those suffering from this often devastating skin disorder are urging appropriate levels of funding for the new institute to insure that its research program will be realized in full and effective fashion.

RESEARCH NEEDS

The ichthyoses are a group of genetic skin disorders which affect the stratum corneum, or outer layer of skin. Four major types of ichthyosis and twenty varieties have been identified. Depending on the type, the skin either grows too fast or is retained too long. In either case, it becomes thick, scaly and dry. It is estimated that over 1,000,000 Americans suffer from some form of ichthyosis, 5,000 of which have the more severe forms.

In the severe and rarer forms of ichthyosis, other diseases may also be present. These may include deafness, retardation, still births and others involving parts of the body vulnerable to this skin disease. People suffering from the ichthyoses experience a number of physical problems as a result of it. Because the skin is thick, it does not breathe and perspire properly and body temperature rises causing serious and critical conditions. Further, even body temperature also rises with exertion in a cool environment, and short exposure to the sun results in severe burning.

The inordinate thickness and scaling of the skin makes it an ideal environment for bacteria and fungal growth. Therefore, infection is a constant problem. It is not uncommon for those suffering from ichthyosis to have complete hair loss, chronic eye-ear infections, irritation, bleeding or blistering of the skin where clothing rubs or pressure is applied to a body part such as when one sits down.

Ichthyosis interferes with the normal physical and psychological development of those suffering from it. Since there is no effective treatment or cure for ichthyosis, care of the skin becomes a constant ritual. Those suffering from the less severe forms are bothered by the daily rituals of trying to exfoliate the skin and soften it. In the more severe forms, life becomes a drudge of daily skin care management. People sleep in plastic wraps and remain "greased" throughout the day. Skin scales are in abundance throughout the ichthyotic home - the dead skin leaving an unmistakeable odor about the person. Some exfoliating treatments contain acids which eat through clothing and furniture. For some, decreased motion due to hard and inflexible skin is a problem - they may be in wheelchairs. In young children, this inhibited motion interferes with the normal exuberance of childhood and has a chronic disabling affect on learning and maturation Because of these chronic motion, thermal and infection problems, adults suffering from ichthyosis are excluded from employment which requires movement or where sanitary conditions and heat is a problem and children do not participate in the normal activities of childhood.

In addition to the physical affects of ichthyosis and the day-to-day drudge of managing it are the social and psychological difficulties encountered because of a shocking physical appearance.

A person's disfigured appearance coincides with the type of ichthyosis they have. Some have red underlying skin with layers of white flakes on top. The taut skin around the eyes and loss of lashes gives them an unnatural appearance. Others have large blackish/brown scales entirely on their skin surface rendering their skin appearance similar to a reptile's. Still others have scales and blistering on reddened skin - all are severely disfigured.

People seeing someone with ichthyosis are often frightened or horrified, shunning the victim. It is not uncommon for ichthyosis sufferers to be stared at, questioned, maligned, teased, and excluded by others due to their disfigured appearance and the observer's unfounded fears of contagion or misunderstanding of the disease.

In our work with ichthyosis sufferers, we note similar psychological characteristics in those who suffer with it. There is a general sense of impairment, shyness, lack of confidence, lack of experience in the developmental tasks of their peer groups, lack of normal social experiences and reclusiveness. These feelings become particularly acute in children as they start school and are out of the protective support of their family for the first time. A pervasive sense of differentness and unworthiness becomes part of the personality resulting in individuals who remain chronically impaired and whose full potential never develops.

The physical, social and psychological problems associated with ichthyosis, particularly in its more severe forms, restricts individuals, keeping them out of the normal mainstream of life and certainly out of the competitive work force. Thus, they are often unable to care for themselves. Along with the other serious diseases which come under the purview of the new institute, the resulting disabilities of those whose suffer from them cost the American economy many billions of dollars each year in medical care, lost wages and productivity, lost taxes, increased disability, and increased social services.

In addition to our urging of appropriate funding levels for hard research, we are also interested in programs that would provide for the immediate supportive needs of these individuals and their families. For example, young parents with no previous history of family ichthyosis, are emotionally immobilized and overwhelmed at the birth of an ichthyotic child. They are isolated, believing they are the only people with the disorder. Some sufferers have never seen another person with the disease and assume no one else has it.

it. Further, there are diagnostic problems. This being a rare disease, many physicians have little experience with it and families often go from doctor to doctor at great emotional and financial expense before getting a correct diagnosis. Ichthyosis sufferers are often unclear about the genetic nature of their disease and society at large has no knowledge of it. Therefore, programs geared toward providing educational and family support services around ichthyosis and the other rare diseases under NIAMS would be of great and extreme help to those suffering from them.

CONCLUSION AND RECOMMENDATIONS

The National Ichthyosis Foundation supports the recommendations of the coalition of organizations concerned with the programs of the National Institute of Arthritis and Musculoskeletal. These recommendations are presented in the coalitions' statement paper of this date. We are aware there are many urgent national needs and limited financial resources. However, since ichthyosis is a genetic defect in the population at large, it will continue to be passed down through the generations until its cause is determined and eradicated. In our view, the extreme disability, disfigurement and impairment experienced by those who suffer from ichthyosis and the other diseases encompassed under NIAMS make funding research to improve the quality of their lives a high national priority. Research into ichthyosis and these other diseases will not only benefit the 50,000,000 Americans who suffer from them, but also the population at large. It is through enhanced knowledge of how these diseases work that we gain a greater understanding of normal life problems, in our case, healthy skin properties - the largest and most apparent organ of the body that most of us take for granted.

We urge Congressional enactment and Presidential approval of appropriations for NIAMS FY 1987 at the level the coalition recommends, as the minimum necessary to firmly establish NIAMS and to begin the research effort essential to finding the answers to the diseases addressed by the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

Your consideration of this issue is greatly appreciated by the National Ichthyosis Foundation and those who suffer from this rare and devastating disease.

Attachments

National Ichthyosis Foundation
Attachment

TO WHOM IT MAY CONCERN REGARDING : ROBERT ANTHONY MASSEY

ROBERT WAS BORN WITH EPIDERMOLYTIC HYPERKERATOSIS (A FORM OF ICHTHYOSIS). THIS CONDITION, THOUGH VERY RARE, IS NOT CONTAGIOUS. UNTIL ROBERT WAS 8 1/2 YEARS OLD, WE KNEW OF NO ONE ELSE WITH THIS CONDITION. WE NOW KNOW OF A FEW OTHERS, BUT NONE LIVE NEARBY.

ROBERT HAS BEEN EXAMINED BY DOCTORS AT DUKE, CHAPEL HILL, AND EMORY, AS WELL AS DOCTORS IN NORTH AND SOUTH CAROLINA. WE ARE IN CONTACT WITH DOCTORS AT THE SAN FRANCISCO MEDICAL CENTER AND THE NATIONAL INSTITUTE OF HEALTH. AT THIS TIME, THERE IS NO KNOWN CURE; THE MOST WE CAN DO IS TO KEEP HIM CONFORTABLE.

ROBERT DOES NOT PERSPIRE, SO WHEN HE GETS HOT, HIS TEMPERATURE GOES UP. IT WILL CONTINUE UPWARD UNLESS HE IS PLACED IN A COOL PLACE. AT 75-80 DEGREES, HIS TEMPERATURE WILL BE 100. HE WILL ALSO GET BLISTERS FROM HEAT OR FRICTION. EVEN IN A COOL ENVIRONMENT HIS TEMPERATURE WILL GO UP WITH EXERTION.

THIS SKIN CONDITION CAUSES ROBERT TO LOOK DIFFERENT. HIS SKIN DOES NOT ADHERE AS IT SHOULD, SO IT COMES OFF EASILY. ALSO, HIS SKIN REPRODUCES FASTER THAN NORMAL. THESE THINGS CAUSE SEVERAL PROBLEMS: (1) IF HE FALLS, THE SKIN COMES OFF EASILY. (2) IF HIT, THE SKIN MAY BLISTER OR COME OFF. (3) A REDUCED LEVEL OF COORDINATION, CAUSED BY STIFFNESS OF THE JOINTS. (4) CLOTHING MUST BE EXTREMELY SOFT TO AVOID RUBBING FRICTION BLISTERS ON HIM.

DUE TO THE PROBLEMS MENTIONED ABOVE, ROBERT MAY DRESS DIFFERENTLY FROM SOME OTHER CHILDREN. HE HAS NEVER BEEN ABLE TO SIT FOR ANY LENGTH OF TIME WITHOUT A CUSHION---PRESSURE FROM HIS OWN WEIGHT CAUSES BLISTERS ON THE BACKS OF HIS LEGS. ALSO, SINCE THERE IS A BUILD-UP OF SKIN ON CERTAIN AREAS OF HIS BODY, THERE IS AN ODOR ASSOCIATED WITH THE CONDITION. THERE IS NOTHING THAT CAN BE DONE ABOUT THIS PROBLEM.

SINCE SEPTEMBER, 1982, ROBERT HAS HAD A STAPH INFECTION ON HIS SKIN. THIS IS A COMMON PROBLEM FOR CHILDREN WITH ROBERT'S CONDITION. HE IS ON A CONSTANT TREATMENT WITH ANTIBIOTICS, AND IS NOT CONTAGIOUS.

WE DESIRE THAT ROBERT BE ACCEPTED AS NORMALLY AS POSSIBLE BY HIS PEERS, AND ANY HELP YOU MAY GIVE HIM IN THAT REGARD WILL BE DEEPLY APPRECIATED.

IF ANY ADDITIONAL INFORMATION REGARDING ROBERT'S PROBLEM IS DESIRED, PLEASE DON'T HESITATE TO ASK HIM OR US ABOUT IT.

MR. & MRS. RICHARD MASSEY
125 BLUE RIDGE DRIVE
FOUNTAIN INN, SC 29644
803 862-4533

NATIONAL ICHTHYOSIS FOUNDATION
A NON PROFIT CORPORATION

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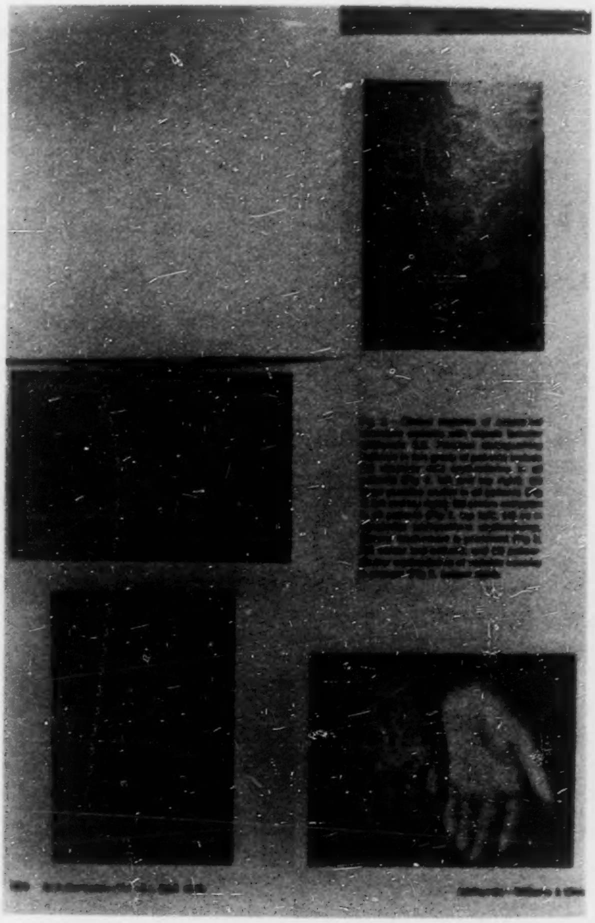

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Mrs. MASSEY. Just as a parent, there is a lot of suffering that goes through the families that have this problem, and especially in our case, it just came up, no past experience on either side of the family.

They did not know the cause of Robert's problems, so there can be no cure yet. We just try to keep him comfortable, so I urge any funding at all to go into research for this to find the cause and find a cure and to make him more comfortable.

It is hard on the families that deal with this day in and day out with a child, that you don't know what to expect tomorrow, because you don't know very many other people with the problem and no one to ask what is going to happen the next day or the next.

Mr. NATCHER. Thank you very much, Mrs. Massey. Robert, we appreciate you coming before our committee, and you come back to see us.

THURSDAY, MAY 1, 1986.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

WITNESSES

WILL WACHTEL, NPF REPRESENTATIVE TO PATIENT ADVOCATE COALITION FOR SKIN DISEASE RESEARCH, PAC-SDR, NATIONAL PSORIASIS FOUNDATION

GAIL M. ZIMMERMAN, EXECUTIVE DIRECTOR

Mr. NATCHER. Our next witness is Mr. Will Wachtel. You have Mrs. Zimmerman with you, and we will be pleased to hear from you at this time.

Mr. WACHTEL. We have some pictures of mild, moderate and severe psoriasis that we would like to show to you.

Mr. NATCHER. Go right ahead now.

Mr. WACHTEL. Mr. Chairman, and members of the subcommittee, my name is Will Wachtel. I am 33 years old and I have had psoriasis since I was 17. I am here today as a volunteer on behalf of the National Psoriasis Foundation to request funding for the new National Institute of Arthritis, Musculoskeletal and Skin Diseases at a level of at least $151,000,000.

We believe that this amount is vitally needed to firmly establish this Institute with adequate staff and, most importantly, to provide for research.

I am here with Ms. Gail Zimmerman, Executive Director of the Foundation, and we are here on behalf of all psoriatics. It is estimated that there are 3 to 8,000,000 Americans who have psoriasis. This equates to 1 in every 30 to 80 people.

Psoriasis is most easily characterized as producing too much skin. Normal skin cells replace themselves once a month, while psoriatic skin cells are supplanted in three days. I have the most common form of psoriasis which appears as reddish, elevated lesions.

Psoriasis can appear or worsen overnight and disappear or improve just as suddenly. It can strike anyone, though heredity is a factor, such as in my family. To me, a tragic fact is that psoriasis can occur at any age.

I have seen photos of children and infants with psoriasis and it disturbs me greatly. Also tragic in the disability psoriasis causes. About 10 percent of psoriatics are so severely covered with lesions that they are functionally disabled and, in a few cases, their lives are threatened.

We don't know exactly how many deaths are causes by psoriasis, but we do know this: It is an emotional killer, a life destroyer. Since our skin is the means by which we initially define ourselves to others, coupled with the fact that we live in a society that places a high value on unflawed physical appearance, people with psoriasis feel uncertainty as to their acceptance.

I have made great leaps in my self-acceptance and worry less about how others react to me, and yet I still will not wear short pants, sunbathe or swim in public. Over the last few years, concealed parts of my body have cleared while my facial psoriasis has spread.

Every day, people stare at me and usually I can deal with it, but when it is really noticeable, it takes great effort to overcome my self-consciousness and leave my house.

I am perturbed that most of the public perception is limited to parodies of "the heartbreak of psoriasis," yet many haven't seen it and they react with the fear of catching it. It is not contagious, but since they don't know that, they shy away. Also, one of the hardest things for psoriatics is that there is no cure.

If I have painted a grim picture, I regret that. But there is hope for psoriatics. Thanks to your previous support, we know much more about psoriasis because the NIH has been the main impetus of psoriasis research in the U.S.

The NIH was responsible for developing a therapy called PUVA, one of the most effective treatments available today. Additionally, the NIH has done work on etretinate, a new experimental drug that is producing results.

With this new Institute, there is an opportunity to achieve greater successes. By its creation, Congress has intended that these diseases receive increased emphasis. We are asking you to carry this intention into reality by appropriating a minimum of $151,000,000.

The past support of scientific research has enabled this country to make tremendous medical advances; now we need to send a message to researchers that we will continue to support their commitment to helping the Nation. Please send this message.

Thank you for your time and consideration of our request. I guarantee you that you have made and can make a difference in the lives of those of us afflicted with psoriasis.

Thank you.

Mr. **Natcher**. Mr. Wachtel, we want to thank you for your appearance before the committee. You have given us a good statement, and we appreciate it.

Ms. Zimmerman, you come back to see us.

THURSDAY, MAY 1, 1986.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASE

WITNESSES

MARY KAYE RICHTER, EXECUTIVE DIRECTOR, NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
SHARON RICHTER

Mr. NATCHER. Our next witness is Mrs. Richter, and we will be pleased to hear from you at this time.

Ms. MARY KAYE RICHTER. Good morning. My name is Mary Kaye Richter, Executive Director of the National Foundation for Ectodermal Dysplasias. I am accompanied by my daughter, who is fortunate enough not to be afflicted with ectodermal dysplasias, but I brought her to see Washington in action.

My appearance at this particular time can best underscore the need for research and support for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

The group that I represent today are the ectodermal dysplasias.

The ectodermal dysplasias are a group of genetic disorders encompassing at least 117 individual syndromes. Each syndrome is identified by two or more derivatives of the ectoderm which do not function or have diminished function. When the term skin disorders is mentioned, it is all to easy to think only of acne and poison ivy.

There are skin disorders that threaten people's lifestyles and change the lives of the families involved.

The ectodermal dysplasias and other skin disorders severely alter the lives of their victims. The patients we represent include those affected by a myriad of medical difficulties. Those with an inability to perspire may experience extremely high body temperatures which may result in paralysis, brain damage or death.

Nearly 25 percent of the families we serve have lost children in their infancy. Other difficulties include sparse hair, absence of teeth, hearing and sight deficiencies, significant respiratory infections, missing limbs, and dysfunction of certain glands such as those producing tears or saliva.

All of these problems are a direct result of malfunctions in the ectoderm. Life for those individuals so affected is altered by an inability to attend school, to participate in activities, or to work in occupations where temperature could be a factor.

The need for treatment for the skin and mouth is continuous. Although the disorders have been documented prior to the time of Darwin, virtually nothing is known about how they happen or the type of medical-dental care which would best meet the needs of the patient.

For parents, the birth of a child affected by a relatively rare disorder is immensely traumatic. This is compounded when you quickly learn that even on the professional level, little information about the disease or treatment is available. How then can we have hope?

The establishment of the National Institute of Arthritis, Musculoskeletal and Skin Diseases is our best hope since ectodermal dysplasias and other related skin disorders were first identified. I am not so naive as to believe that with the development of this Institute that miraculous discoveries about ectodermal dysplasias or other specific skin disorders will occur overnight.

What I do believe is that with sufficient funding for basic skin research, this Institute will yield results which will greatly enhance the chanced for spin-off benefits.

Furthermore, with the increased awareness that this emphasis suggests, those affected by skin disorders will ultimately receive earlier diagnosis, improved information and treatment.

Foremost in my present thoughts are a concern for the level at which the NIAMS will be funded.

Millions of Americans are affected by skin disorders. The costs for treating these disorders alone must be staggering, and when added to the expenses of lost wages and productivity, disability and workers' compensation payments, and increased social service expenditure, we find ourselves burdened by billions of dollars of costs for these disorders.

My own family can expect to pay at least $40,000 in treatment costs for our son affected by ED by the time he reached his 18th birthday, and that does not include any hospitalization costs with may arise.

Placing this Institute among the Nation's highest priorities will, in the long run, serve as a credit rather than as a debit to the Nation's fiscal management.

Great advanced in medical technology have to begin somewhere. Without research, the menace of polio would still be with us, the door to the understanding of DNA would still be locked, and the rejuvenation of the body through organ transplants would not be possible.

Certainly these represent only a fragment of the medical advancements that have been made possible in recent years. But the point here is that they had to begin with research and sufficient funding to make that research possible.

For those individuals affected by skin disorders research remains as the only hope for a chance at not only a normal life span, but also for a nearly normal lifestyle. It is our moral responsibility to see that those persons affected by epidermolysis bullosa, ichthyosis, alopecia areata, psoriasis, ectodermal dysplasias, and other skin disorders have their chance for medical miracles.

I happen to be a farm wife. I know what balancing budgets means all too well. I am the Executive Director of a nonprofit foundation that exists on its own, depending upon individual and group donations for its lifeblood.

But throughout my various life roles, I have learned an important fact; that is, where there is a will, there is a way. If you share our concerns for the health of those suffering and dying from skin disorders, you will help pave the way for a brighter future.

Certainly, the first and perhaps the most important step is the funding of the NIAMS at sufficient levels as to encourage research into basic skin science and research on skin disorders.

My hope is that one day, I may return here to express my appreciation to you for the elimination of some skin diseases, breakthroughs in others, and hope for those that remain.

There currently is no research going on into the ectodermal dysplasias. Disorders have been acknowledged for over 200 years, and yet we remain in almost a fetal stage as far as investigation and research is concerned.

A caterpillar ambling through verdant grass looked up to see a glorious butterfly drifting along on a gentle breeze. The caterpillar thought to himself, "You'll never get me up in one of those things."

Fortunately, not all caterpillars see life quite that way. With the development of NIAMS, we have but a caterpillar, please provide the funding which will permit it to soar.

Thank you for this special opportunity to express my views. I thank you for this opportunity to be here and for allowing my daughter to sit here with me this morning.

Mr. NATCHER. You have made an excellent statement this morning. Sharon we are glad to have you with us.

THURSDAY, MAY 1, 1986.

NATIONAL INSTITUTES OF HEALTH

WITNESS

DR. ROBERT W. KRAUSS, EXECUTIVE DIRECTOR, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY
GAR KAGANOWICH

Mr. NATCHER. Our next witness is Dr. Krauss and our old friend Gar Kaganowich.

Dr. KRAUSS. Thank you for inviting us to visit with you this morning.

FASEB is a nonprofit organization whose purpose is to develop and disseminate new knowledge in the life sciences through its meetings and publications. Our 28,000 members in seven constituent sciences represent research, educational and clinical centers across the United States.

Since our founding in 1912, the Federation has counted 108 Nobel Laureates among its membership. That membership is overwhelmingly composed of working scientists actively engaged in biological and biomedical research, and it is the voice of the working scientist we wish you to hear today.

Let me make it clear that you and this subcommittee have been splendid in your support of basic biological research and, as researchers, we deeply appreciate your commitment to this cause and your sustained efforts on our behalf.

I cannot tell you how much regard exists for this subcommittee among the scientific community in your efforts to help us as you have in the past.

When we came before you last year to testify on funding for the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration, we were very conscious of the impact the enormous Federal deficit could have on support for biomedical research and of the fiscal implications continued high deficits have for the future of all Federal programs.

This year, the compelling new factor is the Gramm-Rudman-Hollings law designed to balance the budget by 1991.

Gramm-Rudman-Hollings could have a devastating impact on basic research. Budget crafters must recognize, however, as they work toward a balanced budget, that basic biological research has a legitimate claim to a reasonable portion of scarce fiscal year 1987 Federal dollars, because it is undertaken for the benefit of all Americans and, I might add, of all mankind.

While the for-profit and nonprofit sectors do make contributions to the support of this research, it is the Federal Government that must shoulder the greatest financial burden if this unique and humanitarian effort is to continue and to pay dividends in the years ahead.

Mr. Chairman, I wish to say that our testimony is a matter of record, as is the proposal for the Ad Hoc Group of Medical Research Funding, a brochure which I am sure you have had made available to you previously. We have c[illegible]s, should that be necessary for you this morning.

We do support the proposal of the Ad Hoc Group. It has been well-detailed with study of the various elements of the budget that you are considering.

I would like to take time, instead of dealing with the prepared testimony, to speak from a lifetime of experiences with the scientists who are finding the knowledge making the cure of the disease possible.

This cadre of scientists is a large number. We have 30,000 members approximately in our organization, and approximately another 30,000 in other societies closely allied to us.

The new and continuing grant number that the Congress generously appropriated last year for 1986 was 6,100 research grants. These are new and competing which go to researchers based on careful peer review, and they are the cream of the crop of researchers, and of ideas of genius that is being put to the task of seeking a cure for disease.

With this number, you will immediately recognize we are funding something in the nature of about 10 percent of the available scientific talent each year that exists out there in the universities and research centers of the Nation.

This is a small number. We took pride in reaching the number of 6,100 this last year, which is a very, very modest increase over long years of being held at just 5,000.

The ideas that are coming from these new research grants are making great gains in our understanding of the cure of a number of diseases, and this has been one of the most exciting times for biomedical research.

The availability of these grants has recruited some of the youngest and best of the minds that we have at our disposal. I wish to simply respond as to why we consider the number of research grants, 6100 we hope this year, somewhere near 6,000, so important.

It is simply because in the absence of Congress' addressing the number of grants, OMB is free to cut back that number to a level such as they attempted this year, to 5,000, which would very seriously cripple the research effort of this Nation.

So, among the many things we wanted to talk to you about, I wish to emphasize the fact that we are dealing on 6100 again this year. We hope that it is possible to specify that number, so we do not risk the cuts we faced last year.

I appreciate the opportunity to be here to talk to you about these matters.

[The statement of Dr. Krauss follows:]

STATEMENT OF DR. ROBERT W. KRAUSS

EXECUTIVE DIRECTOR

FEDERATION OF AMERICAN SOCIETIES FOR
EXPERIMENTAL BIOLOGY

before the

HOUSE APPROPRIATIONS SUBCOMMITTEE
ON
LABOR-HHS-EDUCATION AND RELATED AGENCIES

on the

FY 1987 BUDGET

for the

NATIONAL INSTITUTES OF HEALTH
and
ALCOHOL, DRUG ABUSE AND MENTAL HEALTH
ADMINISTRATION

MAY 1, 1986

Mr. Chairman, members of the subcommittee, I am Robert W. Krauss, Executive Director of the Federation of American Societies for Experimental Biology (FASEB).

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Vaccine development is a good example of the important role the federal government plays in basic research. According to a report on vaccines by the Institute of Medicine of the National Academy of Sciences, "The process of vaccine innovation (from basic research to commercial availability) rarely begins in industry...The basic research necessary to identify pertinent characteristics of the pathogen and host response, often extremely time-consuming and expensive, usually is conducted in federally funded academic or government laboratories, such as those of the National Institute of Allergy and Infectious Diseases..."

There is example after example of the crucial role of federal support in basic biomedical research. Our progress against cancer, heart disease and stroke, to cite just a few areas, is a direct result of federally sponsored research whose primary objective is not profit, but disease treatment and cure as well as a fuller understanding of the processes of life. The success of this unique undertaking depends on the talents and abilities of thousands of dedicated scientists at universities and research centers throughout the United States.

The price of this success is an adequate financial commitment by the federal government, not merely for this year or next, but over the long haul. It is the nature of basic research that it requires a long-term commitment of dollars as well as public patience and trust if there is to be continued hope of producing the life-saving results we all seek.

Dishearteningly, but not surprisingly in view of recent history, the President's fiscal 1987 budget request for NIH is $4.9 billion, a decrease of more than $400 million from the fiscal 1986 congressional appropriation. Under this plan, NIH would support only 5,104 new and competing grants, down from 6,100 in fiscal 1986. The number of research centers would drop from the fiscal 1986 level of 550 to 523 and the number of trainees supported would fall from 9,947 to 9,250. For Alcohol, Drug Abuse and Mental Health Administration research, the Administration is requesting $318.9 million, a five percent decrease below the fiscal 1986 research funding level of $335.6 million. Investigator-initiated new and competing grants would drop from 505 in fiscal 1986 to 448 in fiscal 1987. ADAMHA training programs would be cut back from the $41 million enacted level to only $18.5 million in fiscal 1987.

These proposed cuts are deeply disturbing. The consequences of reduced funding levels for NIH and ADAMHA in fiscal 1987 reverberate far into the future. A research project is not only a sum of money expended over a particular fiscal year--that is only one aspect of this commitment of federal funds. There is momentum to the acquisition of new knowledge, which is lost when federal funding dips unexpectedly. The boundaries between disciplines are increasingly being bridged--a discovery in one area can ignite a whole stream of ideas in another, any one of which can produce long-sought cures as well as important savings in health care costs as long as steady federal funding exists to support these endeavors. The cost of research forgone now cannot be measured by the number of dollars saved and put toward a smaller deficit. Rather, it must be weighed in terms of human suffering not alleviated and the incalculable costs of lost scientific opportunity.

The progress of scientific knowledge and the momentum of discoveries also depends on our ability to recruit and train the next generation of scientists. The Administration budgets for NIH and ADAMHA tell our bright, inquisitive undergraduate and graduate students, our young, promising scientists and our established investigators that a career in federally-sponsored basic biological research may be unreasonably precarious. This instability not only drives trained researchers from the field but discourages promising young people from entering it--losses we cannot afford.

We join with the Ad Hoc Group for Medical Research Funding, a coalition of more than 150 organizations, in recommending a fiscal 1987 funding level for NIH of $6.079 billion. This funding level represents an increase of about $86 million or 1.4 percent over a current services budget. Our recommendation would restore the cuts made by the Administration budget request in a number of areas, including biomedical research support grants, and would continue most NIH programs at their fiscal 1986 level of operation. In addition, the Ad Hoc Group proposal would provide funds sufficient to raise the number of research trainees to the level recommended by the National Academy of Sciences, to upgrade and renovate primate centers and other facilities, to strengthen support for clinical trials through general clinical research centers and increase the number of specialized and comprehensive research centers.

For NIH competing and non-competing research project grants, the Ad Hoc Group recommends a current services dollar level for full funding at study section recommended amounts--a total of between $3.4 billion and $3.6 billion. This level should be sufficient to fund 6,100 new and competing NIH grants in fiscal 1987. FASEB believes Congress spoke strongly and acted wisely in increasing the number of new and competing grants to 6,100 in fiscal 1986. We have fought long and hard to reach this level. FASEB recommends that the 6,100-grant level be maintained in the coming fiscal year and that the number supported by the subcommittee be cited.

The investigator-initiated research project grant continues to be the keystone of the NIH effort because it explores questions at the cutting edge of research, offering the greatest hope for progress against disease. The number of new and competing grants is the key indicator of the health of the NIH research program. If Congress fails to make the grant level a clear priority, OMB has shown it will not hesitate to hold grants near the 5,000 level, a serious setback for research.

For the Alcohol, Drug Abuse and Mental Health Administration we join with the Ad Hoc Group in recommending a research funding level of $465 million. This proposal is consistent with the Institute of Medicine recommendation that ADAMHA's research budget be doubled from 1986 to 1991. This increase would allow for an expanded level of new and competing grants, growth in Research Centers and Research Scientist Development Awards with a focus on young investigators, an increased number of trainees, and badly needed renovation of facilities and equipment.

We urge this subcommittee to continue its enlightened investment in the health of our people, and that of people throughout the world, by providing funding levels for NIH and ADAMHA that allow us to maintain the momentum of biological, biomedical and behavioral research. As working scientists, we assure you that your support, particularly of the individual investigator-initiated research grant, is not only essential to our work, but the reason we have been so successful in our endeavors.

I would be happy to answer any questions you may have.

Mr. NATCHER. Dr. Krauss, we want to thank you for appearing, and Mr. Kaganowich, it is always a pleasure to have you. You have helped us all down through the years, and we appreciate it. We need all the help we can get on this bill.

I say that to you frankly. We hear from the Department of Labor, Department of Health and Human Services, and the Department of Education, and then we have outside witnesses, and we are very much concerned about what you have to say. Statements that you make are important, because we say to the witnesses, Dr. Krauss, from time to time, this is our country, and our money.

We believe this is the most important appropriations bill that we have, as far as the people are concerned. All of health, and all of education funds are in this bill.

Gentlemen, we want to thank you, not only this year, but last year, and all down through the years, and we appreciate it. Thank you very much.

THURSDAY, MAY 1, 1986.

NATIONAL INSTITUTES OF HEALTH

WITNESS

DR. EDWIN CADMAN, PRESIDENT, AMERICAN FEDERATION FOR CLINICAL RESEARCH

Mr. NATCHER. Our next witness is Dr. Edwin Cadman, and we will be pleased to hear from you.

Dr. CADMAN. Thank you, Mr. Chairman, members of the subcommittee. I am Dr. Edwin Cadman, I am Professor of Medicine, University of California at San Francisco.

I am pleased to be here today to present to you the views of the 12,000 members of the American Federation for Clinical Research, AFCR, of which I am President. We are an organization of young clinical investigators whose chief interest is discovering new medical knowledge aimed at the understanding and treatment of human disease.

We are employed throughout the Nation by medical schools, teaching hospitals and research institutions. We are unique in that no single subspecialty dominates our membership.

We place particular emphasis on encouraging young medical researchers, and view the role of Federal initiatives for developing new talent as vital to the advancement of American medicine.

The AFCR is deeply concerned about the appropriation for the National Institutes of Health as are the members of this subcommittee. You have clearly demonstrated your support and understanding of the issues surrounding medical research.

However, this year, the growing budgetary crisis has confronted the Congress with the need to address deficit reduction. All Americans are asking the Congress to make tough choices. We support these national efforts to reduce spending and realign priorities.

But we do not believe that sharply reducing our Nation's investment in biomedical research and development is the best way to accomplish this goal. The appropriation which we support for the

NIH is less than optimal funding, yet will maintain the vitality of the biomedical research enterprise.

We believe that the Nation continues to want improved health and investment in a better future for our children.

The benefits which the Nation receives, and which literally every person receives, from the NIH investment are numerous. There is a direct relationship between the work done in the Nation's research centers and better health care.

The annual expenditure on health care is $2,000 per person, while the annual Federal investment in medical research to reduce the cost and improve health is only $25 per person.

In addition, the Federal investment provides industry with the basic research it needs to produce new products, creates jobs for thousands of workers, and provides the Nation with international prestige as a leader in biomedical research.

Studies show that the rate of return on every dollar invested in medical research is $13. The Nation needs this fuel for its economy. Over $40,000,000,000 is contributed annually to the GNP from medical research discoveries that are now used in nonhealth-related products. These many benefits will not accrue if we do not continue to invest in our future.

The Federal investment in health research and development is largely accomplished through the NIH. Therefore, when the President proposes, as he did in February, to reduce the NIH budget by more than 10 percent, he is actually proposing to slow development of new knowledge and reduce the rate of new medical breakthroughs.

The President's budget would cut spending in every NIH Institute and in every programmatic mechanism. The ultimate impact of such a proposal would be felt by individual Americans, though in the short term, the more obvious loss is the excellent research proposals which go unfunded and the new young researchers who choose other, more stable careers.

The current pace of development of new medical knowledge has been the result of a consistent Congressional investment in the NIH. Advancement in science and medicine occurs slowly; sometimes imperceptibly, across many disciplines.

The Federal investment in medical research has produced a deep reservoir of knowledge and experienced personnel. That reservoir must be continually replenished and young scientists who will provide the new ideas for the next generation must be trained, if we are to achieve the promise of the prevention and care of countless previously intractable conditions.

As an alternative to the President's proposal, the AFCR supports the alternative budget developed by the Ad Hoc Group for Medical Research Funding. This group of over 100 organizations develops each year a responsible NIH budget which addresses what we believe are the reasonable funding needs of biomedical research.

For fiscal year 1987, the Ad Hoc Group for Medical Research Funding proposes that the NIH be funded at the same programmatic level you appropriated in the fiscal year 1986 budget, plus a small amount of growth, 1.4 percent, for one or two especially important programs which deserve additional funding.

To do this would cost $6,079,000,000. The AFCR urges you to carefully consider this "current services" budget which would continue the NIH programs and yet addresses the needs of the Nation for restrained Federal spending.

The AFCR has identified four areas in the fiscal year 1987 NIH appropriation which we believe are especially important for maintaining the pace of medical advancement now and in the years ahead:

One, investigator-initiated grants, at the current level of new and competing renewal awards, should be fully funded at study section recommended levels. Estimated cost: $3,400,000,000 to $3,600,000,000.

Two, General Clinical Research Centers should be fully funded with a slight increase in the number of such centers. Estimated cost: $105,000,000.

Three, research training funds should support the number of trainees recommended, 11,075, by the National Academy of Sciences. Estimated cost: $238,000,000.

Four, research career development awards for young faculty should achieve modest growth beyond last year's level of effort. Estimated cost: $91,000,000.

First, we recommend the level of awards currently being funded should be maintained, and that all investigator-initiated grants be fully funded at study section recommended levels.

This would enable NIH to award grants to approximately 32 percent of approved grant applications, slightly less than the anticipated fiscal year 1986 rate of award, but significantly more than the 27 percent the President's budget would fund.

This is, in fact, a modest request and in keeping with current budgetary constraints.

The AFCR believes that the eventual goal of grants policy should be to support all excellent research opportunities through funding of 50 percent of approved grant applications. This would allow optimal progress and ensure that promising research initiatives were tested.

By maintaining the current level of research grant awards a steady and consistent level of funding would be achieved. This is particularly important to new entrants into the ranks of researchers.

When only a select few of those who apply for NIH funding receive a grant, the perception of the probability of success in a biomedical research career is diminished.

Because NIH provides almost two-thirds of all national support for health-related research and development in the country's centers of higher education, decreases in NIH grant funding have profound implications for medical researchers.

Previous NIH appropriations recommended by your subcommittee and passed by the Congress have provided AFCR's young investigators with a very positive sense of the future in health research.

The AFCR strongly urges you to recommend an appropriation of at least $3,500,000,000 for extramural research grants.

Second, the AFCR recommends that all current General Clinical Research Centers, GCRC, be fully funded and that a few more centers be awarded.

The GCRC program is of special significance for clinical research as a GCRC is both a place for transferring scientific discoveries from the laboratory to the bedside and an entry point for future clinical investigators.

GCRC units have been established at 78 medical centers throughout the Nation. Within each center, patient beds provide a focal point for clinical research, where more than 3,500 projects are conducted each year.

At any one center as many as 100 different projects may benefit from the program.

In addition, the GCRCs are influential in stimulating young researchers through onsite medical student exposure to clinical research and through the very selective Clinical Associate Physician Program. To facilitate the conduct of clinical research the AFCR recommends that at least $105,000,000 be appropriated to the GCRC program.

Third, the AFCR recommends that research training programs be funded at the level recommended by the National Academy of Sciences Congressionally-mandated continuing study of the Nation's overall need for biomedical research personnel.

The NAS Committee recommends that 11,075 trainees should be supported by the National Research Service Awards Program in fiscal year 1987. Each of these training positions can be thought of as nurturing future new developments in medical knowledge.

Analyses of successful new NIH grant recipients show that long and rigorous training is crucial to success as an independent investigator. Both M.D. and Ph.D. graduates and undergraduates benefit; however, the role of the Federally-sponsored research training for physician investigators is particularly important.

The President's recommendation of almost 2,000 fewer trainees would have serious future implications for research. The AFCR recommends that approximately $238,000,000 be appropriated to support all of the NAS recommended trainees.

Fourth, the AFCR recommends that research career awards for advanced fellows and young faculty be fully funded and that modest growth in the number of awards be initiated. The five award programs in the "K-series" are very competitive and provide needed support for competitively selected promising young scientists to make the transition from promising research trainees to successful independent investigators.

Because the number of M.D. investigators has been shown to be declining, the research career awards are particularly critical for clinical research. These awards encourage physicians to continue investigative careers and subsequently to achieve their potential. The AFCR recommends that $91,000,000 be appropriated for such research career development awards.

In summary, the AFCR recommends that your subcommittee support an appropriation of $6,079,000,000 for NIH in fiscal year 1987. This sum would support all of the current NIH research activities while being mindful of the national effort to reduce the Federal budget.

We believe that our request is consistent with the health research needs of the country and takes advantage of the unparalleled opportunities currently available in biomedical research.

If we work together, those opportunities will become new medical cures, treatments and research breakthroughs, and the investment the American people have made in biomedical knowledge will continue to compound.

On behalf of the AFCR, I thank you for your time and will be happy to answer any questions.

Mr. NATCHER. Dr. Cadman, you have made an excellent statement. We appreciate your appearance before the committee. As I have said to a number of other witnesses, you traveled a long way to appear. We appreciate it, and I want you to know that. You come back to see us.

THURSDAY, MAY 1, 1986.

ARTHRITIS RESEARCH

WITNESSES

E. DOUGLAS REDDAN, TRUSTEE, ARTHRITIS INSTITUTE OF THE NATIONAL HOSPITAL FOR ORTHOPEDICS AND REHABILITATION

DR. THOMAS McPHERSON BROWN

Mr. NATCHER. Our next two witnesses are Mr. Douglas Reddan and Dr. Thomas Brown. Come around, gentlemen. We are delighted to have both of you gentlemen before the committee. You have been here before, and we are glad to have you back.

Go right ahead, gentlemen.

Mr. REDDAN. Mr. Chairman, I am grateful to the subcommittee for the opportunity to appear before it once again to address an issue of vital importance to all of us, and in particular to millions of rheumatoid arthritics; namely, the therapy available to rheumatoid arthritics.

I will also speak of the importance of a clinical trial of Dr. Thomas McPherson Brown's antibiotic approach to the treatment of this disease.

For the past seven years, I have commuted each month to Washington from Santa Barbara as a private citizen on behalf of the arthritis problem. I started this monthly pilgrimage because two members of my family were arthritics.

During the past year, unfortunately, two more were added: A sister-in-law, who moved from a non-arthritic in excellent health to a wheelchair-bound cripple in a matter of months; and the second, a young mother of a 3-year-old who went virtually overnight, a few months, to a life-threatening situation from the side-effects of the therapy she has been exposed to.

You will perhaps recall Barbara Matia, a patient of Dr. Brown's from Scottsdale, who has also testified before this subcommittee for the past several years. She couldn't make it today. Her 10-year-old daughter, her mother and her sister were stricken with rheumatoid arthritis since her appearance last year.

Arthritis, as you well know, is an enigmatic disease, it affects patients as young as one year and as old as 90.

Parenthetically, let me say that the implication should not be drawn that the disease is contagious; it is not. What happened to Barbara's family and mine was fortuitous. It does, nevertheless, point up the necessity of being fully aware of the seriousness of the problem.

Dr. Brown's four decades of clinical research on the pathogenesis of rheumatoid arthritis points clearly to an infectious or microbial cause or causes and other researchers are now joining him in this belief.

At an NIH Workshop last November, on the "Infectious Etiology of Early Arthritis," Dr. Lawrence E. Shulman, Director of the newly-established National Institute of Arthritis, Musculoskeletal and Skin Diseases, opened the session by stating, "I believe that Dr. Thomas McPherson Brown has done us all a great service. He has aroused interest in the infectious etiology of rheumatoid arthritis and has persuaded Congress to take an interest in this whole area."

We are grateful for that.

The New York Times stated last December, "If cancer and heart trouble are sentences to death, rheumatoid arthritis is a life sentence on earth." In my seven-year study of the disease, I have learned this lesson well, as you doubtless have long before me.

I am here today to stress what can be done now to reduce the plan, suffering and horrendous cost of this terribly debilitating disease.

As members of the subcommittee, you also have come to know the magnitude of the arthritis problem:

It affects more Americans than any other disease, and 1,000,000 new patients join the existing 37,000,000 yearly. It is the world's most crippling disease.

Therapeutic failure with rheumatoid arthritis is so rampant that the patient's loss of hope can become as great a problem as the disease itself.

The costs are enormous. Not only are there the great emotional and physical costs of living with a debilitating chronic disease, there are the enormous economic costs of medical care and disability payments for those unable to earn a living.

Secretary Bowen estimates the annual cost at $25,000,000,000, and the Arthritis Foundation believes that will reach $100,000,000,000 per year by the end of the next decade.

While $500,000,000 of Federal funds have been spent on arthritis over the past 40 years the drug of first choice for rheumatoid arthritis (gold) has an effectivity record of only 10 percent after five years. It is also reported in the literature to have the highest mortality rate of all prescription drugs.

While the cause, or causes, of arthritis remain elusive, drugs such as gold, penicillamine and placquenil have been shown to modify the progression of the disease, and are approved for that purpose.

Their efficacy varies, however, with time, and their side-effects are highly dangerous. They are often as worrisome to the patient as the disease itself.

Dr. Brown's antibiotic therapy has been used safely and effectively without side-effects for some 40 years, both at George Washington University School of Medicine, where he was Chairman of the Department of Medicine, and later, at the National Hospital in Arlington, where his patients include, among others, members of virtually every branch of the government.

Case reports and anecdotal evidence on more than 10,000 of his patients strongly suggest that antibiotic therapy is of distant value for arthritics.

Since Dr. Brown's antibiotic therapy has not been tested in a controlled clinical trial, and despite the limited and often dangerous results obtained from approved therapies, few in the medical profession are willing to consider using Dr. Brown's antibiotic therapy, as it has not been tested in controlled prospective studies with a large number of patients.

It becomes obvious therefore that the dichotomy that exists between those few physicians willing to use Dr. Brown's unapproved, but long-term effective and safe, antibiotic therapy and those insisting upon staying with a series of dangerous but approved therapies can only be resolved by a full-scale, independent, multi-center, NIH-sponsored clinical trial.

A grant application for such a clinical trial was submitted by the Arthritis Institute to NIADDK last summer. It was rejected without prejudice with specific suggestions relative to resubmission. These have been taken into account and resubmission made just this week.

My purpose in testifying here today is to solicit your support for this long needed clinical trial. I am certain it will document the long-term efficacy and safety of antibiotics for the management of rheumatoid arthritis and lead the way to a far less painful, fear-ridden and costly future for millions.

The immediate result should be FDA recognition of antibiotic therapy as a highly efficacious alternative, leading to its widespread use by clinicians.

Further, prospective proof that antibiotics can effectively control rheumatoid arthritis over the long term, should be helpful to other researchers in deciphering the pathogenesis of this disease.

Thank you very much.

I will be pleased to try to answer any questions you may have. Thank you.

Mr. NATCHER. Mr. Reddan, you have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Reddan follows:]

STATEMENT OF
E. DOUGLAS REDDAN, TRUSTEE

OF THE

ARTHRITIS INSTITUTE OF THE NATIONAL HOSPITAL
FOR ORTHOPEDICS AND REHABILITATION
ARLINGTON, VIRGINIA

BEFORE THE

LABOR - HEALTH AND HUMAN SERVICES - EDUCATION
APPROPRIATIONS SUBCOMMITTEE
"NIH SUPPORT OF A CLINICAL TRIAL OF AN
ANTIBIOTIC THERAPY FOR ARTHRITIS"

HOUSE OF REPRESENTATIVES
MAY 1, 1986

FORMAL PREPARED REMARKS

April 25, 1986

Mr. Chairman and Distinguished Members of this Committee:

I am grateful to the Subcommittee for the opportunity to appear before it once again to discuss Dr. Thomas McPherson Brown's antibiotic approach to the treatment of rheumatoid arthritis. I want to take this opportunity, as I have in the past, to again emphasize the importance of a clinical trial of his therapy for rheumatoid arthritis.

For the past seven years I have commuted each month to Washington from Santa Barbara studying the arthritis problem. When I started this monthly pilgrimage, two members of my family were arthritics. During the past year, unfortunately, two more were added: a sister-in-law - who moved from excellent health to a wheelchair in a matter of months, and then a young mother to a life-threatening situation almost overnight - life threatening in its direst meaning, because of the toxic side-effects of the drugs involved.

Barbara Matia, a patient of Dr. Brown's from Scottsdale, has also testified before this Subcommittee for the past several years. She couldn't make it today; her 10-year old daughter, her mother and her sister were stricken with arthritis since her last appearance. Arthritis, as _you_ well know, is an engimatic disease; it affects patients as young as one year and as old as 90.

Parenthetically let me say that the implication should not be drawn from this recitation of family misfortunes of mine and Mrs. Matia that the disease is contagious; it is not. What happened was simply fortuitous. But it does serve to point out its unpredictability.

All of Dr. Brown's extensive clinical research for the past four decades points to an infectious or microbial cause or causes. Many researchers have now joined him in this belief. At an NIH Workshop on the "Infectious Etiology of Early Arthritis" last November, Dr. Larry Shulman, Director of Arthritis, at NIADDK opened the session by stating, "I believe that Dr. Thomas McPherson Brown has done us all a great service. He has aroused interest in the infectious etiology of rheumatoid arthritis and has persuaded Congress to take an interest in this whole area."

And I am indeed grateful for that.

I am here today to stress once again the criticalness of the arthritic problem and to urge your active backing of our efforts to minimize, if not eradicate, the terribly debilitating effects of this disease. The N.Y. Times stated last December, and I quote, "If cancer and heart trouble are sentences to death, rheumatoid arthritis is a life sentence on earth." In my seven year study of the disease I have learned this lesson well.

On the Subcommittee, you also have come to know the magnitude of the arthritic problem:

- It affects more Americans than any other disease - and 1,000,000 new arthritics join the existing 40 million, yearly.

- Rheumatoid arthritis is the world's most crippling disease.

- Not only is the disease painful and debilitating; therapeutic failure with rheumatoid arthritis is so rampant that the patient's loss of hope can become as great a problem as the disease itself. The drug of first choice, gold, has a 5-year success rate of less than 10%. And has been reported as having the highest mortality rate of all prescription drugs.

- The costs of arthritis are enormous - not only are there great emotional and physical costs of living with a chronic disease, there are the enormous economic costs of medical care and disability payments for those unable to earn a living.

- The Arthritis Foundation recently estimated that by the end of the next decade the costs of arthritis will approach $100 billion per year.

- The cause or causes of arthritis remain elusive. Drugs such as gold, penicillamine and placquenil have been shown to modify the progression of the disease, and are approved for that purpose, but their their efficacy varies and their side effects are highly dangerous - and, are therefore as worrisome to the patient as the disease itself.

Dr. Brown's antibiotic therapy, on the other hand, has been used safely and effectively for some 40 years, both at George Washington University School of Medicine where he was Chairman of the Department of Medicine, and, later at the National Hospital in Arlington where his patients include among others members of virtually every branch of the government, as well as some from overseas. Case reports and anecdotal evidence on more than 10,000 patients treated by his staff strongly suggest that antibiotic therapy is of distinct value for arthritics.

Since his treatment has, however, not been tested in controlled prospective studies with a large number of patients, few in the medical profession are willing to consider using it, despite the extremely poor results obtained from approved therapies.

After a considerable period of time it suddenly became quite obvious to me that the dichotomy of thought that existed between those few physicians willing to use Dr. Brown's unapproved but effective and safe antibiotic therapy and those willing to stay with the dangerous but approved therapies could only be resolved by a full-scale, independent, multi-center tightly-controlled, NIH sponsored, clinical trial - with the benefits to be derived: a safe, effective therapy for millions of arthritics who deserve more than they have received from the 100's of millions of dollars of Federal funds spent on arthritis research to date; on a longer range basis, proof that antibiotics truly work on arthritis will cause more researchers to look for the microbial cause rather than settling for better methods of disease control.

A grant application for such a clinical trial was submitted to NIADDK last summer. It was rejected by the Peer Review Committee with certain suggestions. These have been taken into account and resubmission made in the past few days. My purpose in testifying here today is to solicit your support for this study. I feel quite certain it will document the efficacy and safety of antibiotics for the management of rheumatoid arthritis and lead the way to an eventual cure.

The immediate result should be FDA recognition of antibiotic therapy as a highly efficacious alternative leading to its widespread use by clinicians.

Thank you very much.

I will be pleased to try to answer any questions you may have.

# # #

THURSDAY, MAY 1, 1986.

PARKINSON'S DISEASE AND ALZHEIMER'S DISEASE

WITNESS

ALVIN V. BLOCK, PRESIDENT, ELECTROCHEMISTRY SEPARATIONS ANALYSIS

Mr. NATCHER. Our next witness is Mr. Block. Come around, Mr. Block. We are glad to have you before the committee, and we will be pleased to hear from you.

Mr. BLOCK. Mr. Chairman, and members of the committee, I am Alvin Block, President of ESA, a biomedical research and manufacturing corporation in Bedford, Massachusetts.

Americans are living longer. Behind that positive phenomenon lies a negative reality, those extended life spans are apt to be marred by debilitating diseases.

It is, in fact, the aging of America, that extra stretch of time, which gives prominence to such degenerative diseases as Alzheimer's, Parkinson's and Huntington's as well as disorders such as schizophrenia and depression.

Each is a disease which can devastate its victim, his family and his life savings.

In any given year as many as 2,500,000 Americans, victims of Alzheimer's disease, spend $39,000,000,000 on care.

Huntington's and Parkinson's diseases combined cripple some 500,000 men and women at an estimated cost of $2,500,000,000.

Schizophrenia affects 1,500,000 adults and carries a $30,000,000,000 price tag.

Major depression afflicts some 5,000,000 adults at a cost which cannot even be calculated. Mr. Chairman, we are talking about billions, billions of dollars.

Tragedy links these disorders. Scientists say the chemical makeup of the brain, more specifically the configuration of its neurotransmitters, is the key to the understanding of these disorders.

These chemicals, the brain's switchboard, transmit messages critical to the control of the body and report on its state of health. As the body starts to malfunction, it is reflected in changes in the neurochemical patterns of the brain.

Based on a new unique technology, our company, ESA, a pioneer in biomedical research, has developed an instrument to track these chemicals.

Working with medical researchers from Harvard Medical School, Massachusetts General Hospital and others, we find that biochemical patterns uniquely describe a number of disorders.

Researchers have identified an abnormality in the neurotransmitters of Alzheimer's patients; detected the possible manufacture, by the body, of neurotoxins in Huntington's disease; discovered neurochemical differences among several forms of severe pain; and developed ways of measuring neurochemical patterns in depression and schizophrenia.

Phase II SBIR support from the Division of Research Resources has greatly increased our ability to develop this technology and make it available to the scientific community.

It is critical that this technology be made available to a wide spectrum of key researchers. We ask the committee to ensure that budget cuts will in no way jeopardize this program and its promise of major medical progress.

We support the budget recommendation of the delegation for basic biomedical research for additional funding for biomedical research.

[The statement of Mr. Block follows:]

ESA, INC.

45 WIGGINS AVENUE
BEDFORD, MA. 01730
617-275-0100 • TELEX 923344

Testimony of

Alvin V. Block

President, ESA, Inc.

U.S. House of Representatives

Appropriations Subcommittee on

Labor, Health and Human Services, Education

May 1, 1986

Mr. Chairman and Members of the Committee:

Americans are living longer. Behind that positive phenomena lies a negative reality -- those extended life spans are apt to be marred by debilitating diseases.

It is, in fact, the aging of America - that extra stretch of time - which gives prominence to such degenerative diseases as Alzheimer's, Parkinson's and Huntington's, as well as an increase in schizophrenia and depression.

Each is a disease which can devastate its victim, his family, and his life's savings. These disorders not only tear away at the economy, but weaken the fiber of an otherwise rich human resource.

Let's look at the numbers. In any given year:

- As many as 2.5 million Americans -- victims of Alzheimer's disease -- spend 39 billion dollars on care.
- Huntington's and Parkinson's diseases combined cripple some 500,000 men and women at an estimated $2.5 billion.
- Schizophrenia affects 1.5 million adults and carries a $30 billion price tag.
- Major depression afflicts 4.9 million adults which, when combined with alcoholism and drug abuse, robs the economy of $106 billion.

We are talking about hundreds of billions of dollars, yet these figures do not reveal the loss of productivity or quality of life.

These disorders have characteristics in common. Tragedy is one - emotional and financial to the individual and their family. Scientists say there is another common characteristic that lies in the chemical makeup of the brain. This characteristic is in the difference in the patterns of their neurotransmitters from normal.

These chemicals - the brain's switchboard - transmit messages critical to the function of the brain and report on the state of the body. As the body starts to malfunction, it is reflected in the neurochemical patterns of the brain.

In order to detect and to understand the pathology of such diseases, it is necessary to track these chemicals, and to study their patterns, structure and alignment.

Our company, ESA, a pioneer in biomedical research, has designed an instrument to do just that. In 1984, we built an instrument which, in effect, provides a window to the chemistry of the brain.

Our technology enables us to track, measure and evaluate the behavior of neurochemicals. We find it is the pattern of these neurochemicals which forms a profile of various diseases.

Through the measurement of such neurological patterns we may have in essence, discovered the "blueprint" of a disease. Perhaps, given time and further analysis, we will discover distinctions as fine as that of a fingerprint.

We are, however, a long way from that or from treatment and prevention of these diseases. Nevertheless, the body of scientific knowledge is greatly enriched and growing daily.

While the technology must be given broader exposure, this instrument has so far enabled researchers to:

- identify an abnormality in the neurotransmitters of Alzheimer's patients;
- detect the possible manufacture of neurotoxins, by the body, in Huntington's disease;
- discover neurochemical differences among several forms of severe pain;

- develop ways of measuring neurochemical patterns in depression and schizophrenia.

These studies are being conducted with Harvard Medical School, Massachusetts General Hospital, Boston University Medical Center, Bedford and Brockton Veteran's Hospitals, and McLean Hospital, Belmont, Massachusetts and

are now proceeding at a rapid rate -- thanks to the Phase II SBIR support of the Division of Research Resources at NIH.

Such support enables ESA to automate the equipment and to computerize its data processing operation, making it even more effective.

Using ESA equipment, researchers at Ohio's Wright State University School of Medicine, in collaboration with NASA, were able to distinguish between the neurochemical and biochemical differences of motion susceptible and non-susceptible animals and to develop a pharmacological remedy. The remedy prevented motion sickness in two sets of studies. This promises a similar solution to human motion sickness, post-operative nausea, and nausea resulting from chemotherapy.

It is critical that this technology be made available to key researchers. We ask the committee to ensure that budget cuts will in no way jeopardize this program and its promise of major medical progress. A successful conclusion to this development program should result in a significant contribution to the reduction of national health care costs. With continued support, it is possible that we could see a payback as soon as 3-5 years.

Mr. NATCHER. Mr. Block, you have made an excellent statement. We appreciate your appearance before the committee.

Mr. Block, you are sitting there between two of my friends, Harley Dirks and his son, Dale Dirks. Harley Dirks knows as much about the Labor-HHS-Education Appropriation Bill as anyone in Washington and more than most. For a number of years, he was on the staff of the Senate Committee on Appropriations, working on this bill and he has been good for this country.

I say that to you frankly. He has been good for Congress and good for the people of this country. Dale, the leadership has been established for you. All you have to do is follow in the right footsteps.

We are delighted to have all of you before the committee.

Mr. BLOCK. Thank you.

Mr. CONTE. Harley, before you walk out, I want to echo everything that the chairman has said. If there is a master lobbyist and a real gentleman, it is you.

THURSDAY, MAY 1, 1986.

NIDDKD

WITNESS

DR. SIDNEY BASKIN, CHAIRPERSON, THE FORUM FOR END STAGE RENAL DISEASE NETWORKS

Mr. NATCHER. Dr. Sidney Baskin, we will be pleased to hear from you.

Dr. BASKIN. Thank you, Mr. Chairman, for the opportunity to testify.

I would like to spend some time on some important issues contained in our written testimony. I am Dr. Sidney Baskin. I am a practicing nephrologist and Director of an end stage renal disease facility, by design and training, and a committed volunteer in a network, and President of the Forum of End Stage Renal Disease Networks by circumstances.

I am here today, because I believe in networks and their proven ability to do things, and do them well, to collect valid data, to perform quality assurance, to address patient grievances.

I find myself very depressed and very frustrated at this time because HCFA has proposed rules in the Federal Register on April 15, 1986 that would do the following:

Eliminate a data system that reflects six years of monitoring of patient activity and outcome in all treatment modalities. A system that is validated locally and achieved 100 percent compliance nationwide, and a system that is poised at this time to be converted to the first National End Stage Renal Disease Registry for Dialysis and Transplantation.

The only system that provides information on catastrophic disease in this country. A system that monitors a $2,500,000,000 program, following and monitoring over 85,000 living patients on dialysis, 31,000 transplant patients, and 1500 end stage renal disease facilities, all of which numbers are increasing annually.

Why would we want to eliminate a functional system and replace it with a system that has proven ineffective in the past? If this is allowed to occur, it is incomprehensible to me that quality assurance and patient grievance can be addressed in any meaningful manner.

How can you do quality assurance in the absence of data? There are several false assumptions. One such assumption is that network data are not compatible. Network data is uniform, 100 percent computerized nationwide.

Networks have different objectives, that is another false assumption. Networks have operated with the same goals and objectives for the past four years.

A further false assumption suggests that networks have escalating administrative costs. At a time, over the last eight or 10 years, when we are well aware of inflation in this country, network budgets have been dropped from 6,000,000 in 1980 to $4,800,000 in 1986, despite an ever-increasing workload and level of responsibility.

If this network program ends, everybody will lose. Patients will be disenfranchised, and will not be allowed to participate, to have their grievances responded to, or to have input.

The most successful multidisciplinary team approach to quality assurance and planning ever determined as an effective program in this country will be lost, and you, Congress, will have no data or information about the end stage renal disease program, a $2,500,000,000 program that cries out for the kind of information that allows it to be done effectively, with quality and with cost containment.

I sit before you representing a committed, dedicated, caring group, which include professionals, staff, patients and families, most of whom are volunteers, which explains why the work of this program has been so successful with small amounts of money.

We don't know how to preserve the program, but we know it needs to be preserved. I don't want to see undone what Congress compassionately put into place when they responded to the end stage renal disease community in 1973 with history-making legislation that developed a program without precedent, and one that I am proud to have worked with, and one that I believe has accomplished its goals remarkably successfully.

Thank you for the opportunity to testify before you today.

[The statement of Dr. Baskin follows:]

TESTIMONY TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION AND RELATED AGENCIES

ROOM 2358, RAYBURN HOUSE OFFICE BUILDING
TUESDAY, APRIL 29, 1986, AT 11:50 A.M.

FROM
SIDNEY BASKIN, M.D., PRESIDENT
THE NATIONAL FORUM OF END STAGE RENAL DISEASE NETWORKS

OFFSET
CAMERA COPY

WRITTEN TESTIMONY FROM SIDNEY BASKIN, M.D., PRESIDENT
THE NATIONAL FORUM OF END STAGE RENAL DISEASE NETWORKS
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION APPROPRIATIONS OF THE HOUSE OF REPRESENTATIVES

Unfortunately, I feel that I must come to this Subcommittee with a very grave message. The Health Care Financing Administration has proposed rules in the Federal Register on April 15, 1986, that would redesignate existing network areas and reduce the number of networks to the smallest practicable number, presumably 14. These rules would dismantle the existing intranetwork structure of communication and responsibility for quality assurance through the Medical Review Board, and eliminate access to data to those responsible for monitoring the quality of care for this $2 billion federal catastrophic health care program.

Since 1981, Networks' representatives have appeared before this and other Congressional committees urging the continuation of existing networks. Networks have had a critical role in the collection and validation of all national Medical Information System patient-specific data. They have also established uniformity in such data nationwide through voluntary efforts. In addition, Networks have a unique role in utilizing local data for quality assurance and the resolution of patient grievances. It must be obvious that to meet the needs of patients, providers, the Health Care Financing Administration, and the Congress for cost-containment and quality assurance that data are essential. To remove access to patient-specific data from the very organizations charged with quality assurance and resolution of grievances is incomprehensible. Should these proposed rules go unchallenged, the "network organizations" would be emasculated. Further, it is contradictory for the President to express interest in exploring catastrophic disease coverage and, at the same time, dismantle the only federal program that collects data and monitors quality of services provided for a catastrophic disease.

If this doesn't concern you, let me describe for you a future in which there aren't 32 Networks. This is the near future, perhaps as soon as this autumn. You will try to get data on the current size of the kidney failure population and know something about their treatment choices. BUT, you will be frustrated because the data collected by HCFA will be old and filled with holes. On top of this, it will take HCFA months to respond to your request because it simply won't have data without Networks.

Questions have been raised as to why Networks per se are needed for the existence of a national ESRD patient registry. It has been argued that data could be collected by a private contractor. This approach was tried at the initiation of the ESRD program with a contract with Value Engineering. The effort failed. HCFA then began collecting data directly from facilities. Their efforts resulted in a less than 50% compliance rate. Frustrated by these poor results and growing criticism from both Congress and the renal community, HCFA turned to Networks and, without additional funding, required them to be responsible for the collection, validation, and submission of all aggregate facility survey data, as well as all patient-specific dialysis and transplant forms from over 1100 certified facilities.

Within the first year, Networks demonstrated their ability to collect data with a 100% compliance on the semi-annual MIS Facility Survey. This compliance rate has been duplicated during each of the past six years. It is from these Facility Surveys that HCFA's ESRD Annual Report to Congress is written and you obtain your information each year as to the number of patients on dialysis, their treatment settings, and the number of patients receiving kidney transplants.

We have today the same concerns and the same messages as in the past. If the Administration's proposal to separate and dismantle the data system and the Network organizations goes unchallenged or if Congress allows the Administration to succeed at its proposal to spend but $1 million on Network organizations in fiscal year 1987, Congress will eliminate the opportunity to enhance the national ESRD Medical Information System so that it can meet the country's needs.

End Stage Renal Disease Network Coordinating Councils perform all of the functions that you and the Health Care Financing Administration need to:

Monitor and assure quality of care
Ensure that patients have a voice in their treatment
Promote patient rehabilitation
Collect valid data for analysis
Enhance the effective and efficient administration of Medicare benefits

—

The 32 ESRD Networks are similar to the representatives in Congress. Like congressional districts, Networks were designated along historically similar geographic areas and thus, represent local concerns. Networks work closely with kidney failure patients and the medical community that serves them. Networks know their constituents just as you know yours and in a manner that no government bureaucrat will ever replicate.

Consequently, I urge your support for the existing network system and the defeat of the April 15, 1986, proposed rule. In addition, I urge you to reinstate funding for ESRD Networks at a level of $7 million in the fiscal year 1987 budget. It is only through the 32 ESRD Networks that you will be able to properly serve the 90,000 voters currently with kidney failure and all those that will be diagnosed in the future. We need you to respond favorably, just as Congress responded positively and compassionately in 1973 to make life-saving transplant and dialysis therapy available to Americans in need. I thank you for the opportunity of presenting this testimony and for your continued support of our program.

Mr. **Natcher**. Thank you.

Dr. **Baskin**. I did bring some charts which indicate some of the data that networks have collected in the areas, modalities of treatment, outcome results and other such information.

Mr. **Natcher**. Thank you very much, Dr. Baskin, you have made an excellent statement. We appreciate your appearance before the committee.

Thursday, May 1, 1986.

TITLE V OLDER AMERICANS ACT

WITNESS

ROBERT A. DENMAN, ASSISTANT, LEGISLATIVE SERVICES, NATIONAL FARMERS UNION

Mr. **Natcher**. Our next witness is Mr. Denman.

Dr. Denman, come right around, Doctor.

We are glad to have you before the committee.

Mr. **Denman**. Thank you very much for asking us to appear. I am Robert A. Denman, Legislative Assistant, on behalf of the National Farmers Union, testifying on behalf of Title V of the Older Americans Act.

In the interest of some time, I will ask my complete statement be inserted in the record.

Mr. **Natcher**. That will be fine.

Mr. **Denman**. The National Farmers Union has been coming before this subcommittee for 20 years, ever since the Green Thumb Program was originally proposed by our then-President Jim Patton, who proposed that the green thumbs of retired farmers be put to work.

It started out in terms of developing some roadside beautification projects and since that time, that program has been expanded where Green Thumb Program helps in a variety of other ways, rural communities, providing employment services, opportunities to older Americans.

We now help out the schools and in terms of keeping public libraries open. Since our program was originally proposed as of last grant year, there were 18,478 older Americans currently enrolled in the Green Thumb Program, half between 60 and 70 years of age, and 86 percent had family incomes below the poverty level.

When this program was originally proposed, we were going through an outmigration from the family, and today, we are going through that situation once again.

One understands that many of these farmers are older farmers, going out of business not necessarily because they want to, but because they are being forced to. They now have to go back out on the job market and this program helps them.

Basically, what we are asking for is continuous support for the entire Title V program. We are not the only ones who help out in terms of trying to provide employment opportunities for older

Americans, most of whom continue to be very productive on the job market.

Our focus is on Title V, we want to emphasize the importance of continued funding at least at current service levels for all titles under the Older Americans Act.

It must be maintained to assist a rapidly growing older population, Mr. Chairman. I will conclude it at this time.

Mr. NATCHER. Mr. Denman, we appreciate your appearing before our committee at this time. Thank you very much.

[The statement of Mr. Denman follows:]

NATIONAL
FARMERS
UNION

STATEMENT OF

ROBERT A. DENMAN
LEGISLATIVE ASSISTANT
NATIONAL FARMERS UNION

TO THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

11:55 A. M., MAY 1, 1986

REGARDING

APPROPRIATIONS FOR THE SENIOR COMMUNITY SERVICE
EMPLOYMENT PROGRAM
TITLE V OF THE OLDER AMERICANS ACT

600 Maryland Avenue S.W. • Suite 202 • Washington D.C. 20024 • Phone (202) 554-1600

STATEMENT OF

ROBERT A. DENMAN
LEGISLATIVE ASSISTANT
NATIONAL FARMERS UNION

TO THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
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U.S. HOUSE OF REPRESENTATIVES

MAY 1, 1986

REGARDING

APPROPRIATIONS FOR THE SENIOR COMMUNITY SERVICE
EMPLOYMENT PROGRAM
TITLE V OF THE OLDER AMERICANS ACT

Mr. Chairman:

We appreciate the opportunity to present testimony to the Subcommittee on Labor, Health and Human Services in support of FY 1987 appropriations for the Senior Community Service Employment Program, Title V of the Older Americans Act.

National Farmers Union is proud to continue 20 years of sponsorship of the Green Thumb program which provides employment opportunities for older, economically disadvantaged men and women in the rural communities in which they reside across the nation. In 1965, National Farmers Union proposed to take the green thumbs of older and retired farmers and put them to work to beautify our highways. These were people who had been caught in the backwash of a revolution in agriculture and a migration of young people to jobs in the cities. They had little or no Social Security coverage because farmers were not brought under the program until 1955 and earnings were often low. But, they did have a lifetime of experience and a commitment to work and use their skills productively.

From that small beginning, we have expanded the variety of jobs from parks and trails and highway reststop projects to provide enrollees with opportunities to help rural schools in the education of young people, to help with transportation needs for older, isolated rural citizens, and to help in small towns, nursing homes, libraries and senior citizen centers.

Green Thumb temporarily assigns enrollees to host agencies which operate community service programs contributing to the maintenance and growth of local communities. Assignments are made for an average work week of 20 hours and enrollees are placed in those positions which best use their talents, interests and ambition.

Another of Title V's objectives is to encourage unsubsidized employment for their enrollees, with better wages and more hours and fringe benefits. When needed, they provide training and work experience as need is determined through periodic individual assessment.

We must report that troubled farmers have completed a full cycle. Low farm prices and related problems have driven thousands of farm families from their life's work in the last few years. Economists predict that 10% of this nation's farmers will be driven from farming in the next two years, according to a

December 24, 1985, article in the Wall Street Journal. Twenty percent are in deep trouble with a rippling effect of $25 billion farm-loan default and $30 to $50 billion cumulative reduction in real GNP over the next 8 years impacting in the whole national economy.

Green Thumb now is trying to help bankrupt farm men and women and their neighbors who meet Title V eligibility find a place earning a small weekly check to buy groceries and shoes and gas for the car. These people need help in beginning new careers, training and job placement skills that can build on the lifetime skills of "just a farmer."

Mr. Chairman, we are grateful for the interest and support which you and members of this Committee have shown to the Senior Community Service Employment program over the years. Increases in funding levels -- sometimes generous though not overly large in relation to need -- have made it possible to expand the opportunities for older workers, to extend services to their communities and supplement their own limited income. Although the program may seem small in relation to the eligible population, it produces a large multiplying effect in service to the communities it serves.

Seven other national organizations have joined in the effort to promote employment of older men and women since Green Thumb pioneered the concept two decades ago. They are: National Council of Senior Citizens; American Association of Retired Persons; National Council on Aging; U.S. Department of

Agriculture, Forest Service; National Urban League; National Center on Black Aged; and National Association of Pro Spanish Speaking Elderly.

The governors also receive part of the funds and many of the state aging agencies are asked to administer the program. This brings a variety of expertise and organizational support to the effort to demonstrate the effectiveness of using older workers to provide needed services to their neighbors and in their own communities.

Improved health, longer life expectancies, dramatic changes in the workplace and the aging of the post-World War II "baby boom" generation have forced a new look at older workers, according to the Ninth Annual Report on Older Workers by the National Commission for Employment Policy. For most older workers, age is an advantage, but for some 5 million, or 10%, of today's older workers the picture is not so good. Older workers who lose their jobs, or are members of minority groups, as well as many older women and those older workers who have health problems, often face serious problems in the labor market.

There is no denying that age discrimination exists. For many of the 5 million workers noted above, their problems are rooted in a lifetime of low levels of education, inadequate training, irregular work experience, poor health, occupational segregation, or sex and race discrimination.

Green Thumb has always endeavored to reach out to those most in need of an opportunity to work, and many of them had limited chance for education and training. There were 18,478 older workers enrolled in Green Thumb at the end of the last grant year, June 30, 1985. Half of them were between 60 and 70 years of age, and almost a fourth were over 70; 86% had family income below the poverty level. Over 7,000 had an 8th grade education or less, 4,017 attended 9th to 11th grade, and 5,387 more completed high school. Women made up 61% of the enrollmen and 18% were minorities.

The Commission cites the Senior Community Service Employment Program, the Job Training Partnership Act, and the Employment Service as the major government-sponsored efforts to address the needs of this large pool of disadvantaged older workers.

The Senior Community Service Employment Program will suffer the 4.3% cut in funding mandated by the Gramm-Rudman-Hollings Balanced Budget Amendment when grants are executed by the Department of Labor on July 1, 1986, to commit the FY 1986 appropriations for Title V. This cut in funding will be absorbed through attrition of enrollees who leave the program for unsubsidized jobs, or retire from their assignment. This will, of course, mean a reduction of service to the community organizations and local branches of government who at the same time are suffering funding cuts from other sources. While we hope it will have the least disruptive impact on those workers who have found it necessary to supplement their limited income, it will also further limit employment opportunities to the thousands of eligible men and women who need the opportunity to work.

Green Thumb continues to make every effort to reduce the administrative costs of operating the program and has been successful to the degree that they will put as much of their new grant in enrollee wages next year as was going to workers four years ago, even with the Gramm-Rudman 4.3% cut in funding. They will continue to look for administrative efficiency, but it must be recognized that the continued high quality of a program does require supervision by skilled and experienced staff to maintain the broad mandate of the Senior Community Service Employment Program.

Title V is an employment and training program and a major purpose is to train older workers for better jobs. It is intended as a means to an end. It is a new beginning. In addition to the on-the-job training that enrollees receive while working with their host agencies, our Green Thumb staff helps them find opportunities for training and development which will enhance their performance and help better prepare them for their community service jobs as well as placement in unsubsidized jobs. This may include a brush-up typing course, or a more extensive introduction to word processing and computers provided through the vocational education programs, the local high school, or even access to a typewriter at their host agencies during off-duty hours. Many enrollees need to undertake training for a completely new field of employment, such as health care or high tech assembly.

Congress directed that 3% of the funds appropriated for Title V be made available for experimental training programs to help older workers move into jobs in private industry. Green Thumb has carried on several such projects, one of which has focused on training older workers as health care para-professionals in order to work in nursing homes or provide vitally needed home health care which appears to be one of the most rapidly growing areas of demand for trained personnel. Such training programs can be replicated by other organizations through the help of a handbook which Green Thumb developed from their experimental programs.

In the interest of expanding the numbers of opportunities for older people needing employment, we have actively reached out to work with the Job Training Partnership Act (JTPA) at the local and state level. Congress directed that 3% of the JTPA funds be targeted toward expanding employment opportunities for older workers in the private sector, and Green Thumb has been anxious to cooperate in making use of those funds for productive opportunities for older people in the communities in which Green Thumb projects are located.

In several states, Green Thumb has been asked to administer a part of those funds. In many other cases, we have actively promoted coalition activities that will make the most productive use of the resources of both JTPA and the Senior Community Service Employment Program. We find that they can complement one another because JTPA by and large cannot provide stipends to help older workers while they attend extended training courses, and Title V is complemented by the classroom training resources that can be made available through JTPA. Green Thumb and JTPA have also cooperated on recruitment, follow-up and placement assistance to help both employers and workers.

Such coalition building is time consuming for Green Thumb staff, but they feel that earlier efforts are beginning to pay off in terms of more cooperative working relationships with JTPA staff and local employers. Green Thumb is anxious to make the best use of all available resources, recognizing that SCSEP provides only 65,000 employment opportunities, or only about 1% of the jobs that are needed by those who are eligible for the program. We are actively seeking ways in which to complement the work of the Job Corp in those areas where they have training centers. The Assistant Secretary of Labor has directed that older workers be utilized in areas of supportive training so that they can serve as role models for the younger workers. We believe it can be a most productive effort and builds on a Green Thumb demonstration program some years ago of a younger worker/older worker employment training program that was also funded by the Department of Labor.

We believe the Senior Community Service Employment Program demonstrates the effective use of Federal funds to assist in the employment and training of older workers as well as the unmet needs of the local branches of government and non-profit organizations to deliver service in communities across the nation.

We were glad to note that the Reagan Administration included in their FY 1987 budget the sum of $326 million for the Senior Community Service Employment Program.

We recognize that the House has not yet moved on their FY 1987 budget resolution and may not do so before you mark up your own appropriations bill. But we understand the House Committee on Education and Labor has recommended to the House Budget Committee that a variety of employment programs be funded at current service levels which would include a 5% inflation increase.

A trained and employed work force, along with our natural resources, is the basis for the wealth of our nation. Today 8.5 million persons are officially unemployed. But counting part-time and discouraged workers who would take full-time work if it were available, the total is over 15 million. The Congressional Budget Office reports that each percentage of unemployment costs the federal treasury $40 billion in lost tax revenue and increased transfer payments. Certainly one of this nation's highest priorities and moral imperatives must be to effectively use our great human resources. Investment in job training and employment programs can be the basis for sound economic growth.

While we have focused our testimony on the Senior Community Service Employment Program, we want to emphasize the importance of continued funding, at least at current service levels, for all titles of the Older Americans Act. The support and coordination of the aging network must be maintained to assist a rapidly growing older population.

Almost one-third of Green Thumb workers furnish services to the elderly. Over 1,900 work in nutrition programs and 1,285 serve in senior centers, while more than 500 provide health and home care and an equal number fill needed services through outreach and referral to community agencies. Over 350 help in vital transportation services. Reductions in funding for other programs under the Older Americans Act are immediately reflected in increased requests for help from Title V enrollees to assist in unmet service needs.

We would also urge maintenance of current service levels for Title IV of the Older Americans Act which provides needed resources for research, demonstration and training in the fields of aging.

We urge, that in consideration of FY 1987 funding, you make every effort to maintain the current services funding level which recognizes an inflation factor for the Senior Community Service Employment Program and other Older Americans Act programs so that Green Thumb and others administering this program can continue to find new ways to meet community needs through host agencies and help older workers with the employment training they need to move on to being productive, tax-paying members of their communities, WORKING HARD, WORKING WELL, AND WORKING PROUD.

Thank you, Mr. Chairman.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

CHRISTINE LUBINSKI, WASHINGTON REPRESENTATIVE, NATIONAL COUNCIL ON ALCOHOLISM

Mr. NATCHER. Come on around, Ms. Lubinski, we are delighted to have you, and we are sorry that we have been delayed because of all of these roll call votes. We will be pleased to hear from you.

Ms. LUBINSKI. Thank you very much, Mr. Chairman.

My name is Christine Lubinski, and I am the Washington Representative for the National Council on Alcoholism.

NCA is the Nation's leading nonprofit health organization working nationwide to prevent and reduce alcoholism and alcohol-related problems. NCA's two major missions are public education and public advocacy. We have 184 local and State affiliate councils.

In 1985, NCA published a fact sheet on alcoholism and alcohol-related problems which indicates that 12,100,000 adult heavier drinkers have one or more symptoms of alcoholism.

Alcohol problems cost the Nation more than $116,000,000,000 annually and may be responsible for up to 15 percent of the Nation's health care costs. Alcohol use during pregnancy is one of the leading causes of mental retardation.

The three major causes of death for young Americans, accidents, homicide and suicides, are all significantly associated with alcohol. As mortality rates for all other age populations drop while teenage deaths rise, 30 percent of fourth graders—nine-year-olds—report peer pressure to drink alcohol, in a 1983 Weekly Reader survey.

The extraordinary funding limitations on alcohol research are a matter of historical record. We remain far from our goal of realizing the $100,000,000 NIAAA research budget recommended by the Institute of Medicine.

In fact, the President's 1987 budget request for NIAAA represents a significant retreat from this goal.

The President's request for NIAAA is $68,800,000, a $1,400,000 reduction over the 1986 appropriation level before sequestration.

A commitment to Federal health research has long been a hallmark of this committee's work. We encourage you to underscore your support for research efforts aimed at the prevention and treatment of alcoholism and alcohol-related problems by appropriating funding for NIAAA activities at levels sufficient to maintain the integrity of the Institute's various functions.

NCA recommends a $72,000,000 appropriation for NIAAA research. This would provide a 15-percent increase in the number of research project grants, and increase investigator-initiated project grants by 16 percent over 1986.

It would allow for some expansion of the existing alcohol research centers, and fund two new centers: Alcohol and High Risk Populations and Alcohol and Immunology.

We propose an increase in funding for research training to $1,800,000 to finance 80 trainees. The Administration's $1,300,000 request for this line item would decrease the number of trainees from the current 66 to 63.

NCA urges a $1,000,000 appropriation for the NIAAA clinical training program. The import of research findings regarding the identification and treatment of alcoholism depends on the dissemination of these findings to clinicians as well as students in the health and social services disciplines.

Thank you very much, Mr. Chairman.

[The statement of Ms. Lubinski follows:]

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STATEMENT OF THE

NATIONAL COUNCIL ON ALCOHOLISM, INC.

Presented by Christine Lubinski,
Washington Representative

to the

Subcommittee on Labor, Health and Human Services,
and Education
Committee on Appropriations
United States House of Representatives

on Fiscal Year 1987 Appropriations for
the National Institute on Alcohol Abuse and Alcoholism,
and the Alcohol, Drug Abuse and Mental Health
Services Block Grant

Thursday, May 1, 1986
12 Noon

NCA is a private nonprofit health organization

The National Council on Alcoholism is the nation's leading nonprofit health organization working nationwide to prevent and reduce alcoholism and alcohol-related problems. NCA's two major missions are public education and public advocacy. We have 184 state and local affiliate councils on alcoholism which provide information and referral services to families and individuals with drinking problems, and many of these local councils conduct prevention and education programs and involve citizens in grassroots advocacy efforts.

NCA's principal concerns in the federal budget are the research and prevention initiatives of the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the treatment services provided under the Alcohol, Drug Abuse and Mental Health Services (ADMS) block grant. NIAAA represents the heart of the federal alcoholism effort, as it illustrates the strong, ongoing commitment of the federal government to address a major public health problem while providing funding for research which may hold the key to new and innovative strategies to identify, to treat, and ultimately to prevent alcoholism and alcohol-related problems. The ADMS block grant offers critical federal dollars to augment the nation's public treatment system and lends national leadership to the states by identifying the enhancement of alcohol and drug services for women and prevention initiatives as critical items for federal support.

In 1985, the National Council on Alcoholism published a fact sheet on alcoholism and alcohol-related problems with the cooperation of NIAAA and the National Clearinghouse on Alcohol Information which indicates that 12.1 million adult heavier drinkers have one or more symptoms of alcoholism. In some respects, these numbers represent only the tip of the iceberg of alcohol problems which continue to undermine the nation's health and economy. Alcohol problems cost the nation more than $116 billion annually and recent estimates indicate that alcohol abuse may be responsible for up to 15 percent of the nation's health care costs. Numerous studies have indicated that alcohol is the principal agent involved in major forms of trauma. Injuries kill more Americans aged 1-34 than all diseases combined, and they are the leading cause of death up to age 44. Alcohol use during pregnancy is one of the leading causes of mental retardation and the only preventable cause among the top three. The three major causes of death for young Americans, ages 15-24--accidents, suicides and homocides--are all significantly associated with alcohol. As mortality rates for all other age populations drop while teenage deaths rise, 30 percent of 4th graders report peer pressure to drink alcohol in a 1983 Weekly Reader survey. The high incidence of youthful drinking poses a serious threat to the healthy development of American children. Unlike many other health problems, alcoholism and heavy drinking are also associated with a myriad of other community problems including violent crimes of every description, domestic violence, child abuse and teen pregnancy.

The complexity of alcoholism and alcohol-related health and social problems pose a tremendous challenge to the federal government and its leading alcohol agency, NIAAA. Research needs span a large number of diverse areas including genetics and molecular biology, biochemistry and metabolism, the neurosciences, as well as behavioral and environmental anticedents, incidence and prevalence data collection, and prevention and treatment studies. The needs are great and the resources are limited.

The extraordinary funding limitations on alcohol research are a matter of historical record and need not be reiterated again here. We remain far from our goal of realizing the $100 million NIAAA research budget recommended by the prestigious Institute of Medicine. In fact, the President's 1987 budget request for NIAAA represents a significant retreat from the Institute of Medicine report goals as well as the Congressional committment to enhancing alcohol research reflected by substantial increases in NIAAA appropriations over the last three years.

The 1987 President's request for NIAAA is $68.8 million -- including $56.6 million for research; $1.3 million for research training; and $10.9 million for direct operations. Although this request reflects an increase of $1.9 million, or 2.8 percent over 1986, this small increase must be viewed in the context of the 4.3 percent reduction in NIAAA programming for 1986 under the Gramm-Rudman-Hollings amendment. In this context, the President's request represents a $1.4 million reduction over the 1986 appropriation level before sequestration. The research request would hold the number of new and competing grants at 74, compared to 100 in 1985 and 1986 -- a 26 percent reduction. The research training request is $1.3 million, reflecting a decrease of $.1 million, or 7.6 percent from 1986 (a decrease of 11.5 percent from 1985). The request will support 63 trainees, compared to 69 in 1985 and 66 in 1986. The $10.9 million request for direct operations reflects a net decrease of $.3 million from the 1986 revised figure and a $.8 million reduction from the 1986 appropriation level prior to sequestration.

Unfortunately, this proposed retrenchment in federal support comes at a time when the promise for research findings which might contribute significantly to the alleviation of alcoholism and alcohol-related problems greater than ever. At a time when the interest of scientists in alcohol-related research is stronger than ever before in history, grant opportunities are shrinking and research training monies are reduced. Research is providing increasing evidence that heredity is a major contributing cause of alcoholism in a large proportion of cases. There are important studies under way to analyze the differences among population groups in terms of drinking behavior and the incidence of various types of alcohol problems in order to identify subgroups at higher risk. Relatively new prevention research which explores the way controlling the availability of alcohol can contribute to a reduction in alcohol-related problems offers a fresh and complementary area of study to more traditional biomedical and educational initiatives.

A commitment to federal health research has long been a hallmark of this Committee's work. In this regard, we encourage you to underscore your support for research efforts aimed at the prevention and treatment of alcoholism and alcohol-related problems by appropriating funding for NIAAA activities at levels sufficient to maintain the integrity of the Institute's various functions and to ensure the continued growth of this relatively new research discipline.

The National Council on Alcoholism encourages the Subcommittee Members to appropriate $72 million for the NIAAA's research budget. An appropriation at this level would provide a 15 percent increase in the number of research project grants supported by NIAAA and award 116 new and competing investigator-initiated project grants, an increase of 16 percent over the number awarded in 1986. In addition, this funding level would allow for some expansion of the existing alcohol research centers and fund two new centers on Alcohol and High Risk Populations and Alcohol and Immunology.

We recommend an increase in appropriations for research training to $1.8 million to finance 80 trainees. The Administration has proposed a decrease in this line item even as new scientific avenues of investigation are being explored to answer key questions about the etiology and prevention of alcoholism and alcohol-related problems.

NCA proposes a $1 million appropriation for the NIAAA clinical training program. The import of research findings regarding the identification and treatment of alcoholism depends, in large measure, on the dissemination of these findings to practicing clinicians as well as students in the health and social services professions. Funding for NIAAA's clinical training program has been non-existent for a number of years now, resulting in a critical information gap between researchers and clinical professionals. A $1 million appropriation would offer an important signal to the alcoholism field suggesting a renewed commitment to the importance of clinical training to successfully identifying and treating this illness.

Under the Administration's request, NIAAA would receive only $10.9 million for direct operations. Currently, many NIAAA prevention initiatives as well as collaborations with private sector organizations to disseminate alcohol-related health information to key target populations and to the general public are funded through the direct operations budget. The most substantial reductions in Institute activities, both under the Gramm-Rudman-Hollings amendment and under the President's 1987 request, occur in the direct operations line item. It is precisely in these activities, which nurture important partnerships with the private sector in the generation of public education and prevention activities in local communities, that the efforts of NIAAA are most immediately visible and meaningful to the American public. These cuts threaten to severely curtail that visibility as well as the hope and energy it engenders in individuals, families and communities committed to reducing alcohol-related problems. Moreover, the financing of prevention efforts under the same line item with NIAAA staffing and other basic administrative costs makes little sense as it places valuable prevention activities in competition with the maintenance of NIAAA's basic management and operational functions.

We propose that either a separate line item for prevention and knowledge transfer activities be provided, or that the conference report accompanying the appropriations bill specifically direct the Institutes to refrain from reducing the prevention and knowledge transfer activities by an amount greater than the reduction incurred by the other activities supported by the direct operations line item. Moreover, we strongly recommend an appropriation of $13.2 million for direct operations to facilitate NIAAA's many critical functions.

The President's 1987 request of $490 million for the ADMS block grant is the third consecutive Administration's request to hold federal treatment dollars at this low and stagnant level. Unfortunately, appropriations for the block grant have been held to this level. The 1986 sequestration of funds against the block grant appropriation will result in a decrease of $21,070,000 in discretionary funds available to the states this year. If this information is placed in the context of the 40 percent reduction in federal treatment monies to states when the block grant was implemented in 1980, nothing less than a severe erosion of the publicly-funded treatment network in the nation can be expected. The last reauthorization of the ADMS block grant called for new and expanded services for alcoholic and drug-addicted women, with a federal mandate that states spend 5 percent of their block grant award to implement this provision. We urge the Subcommittee to appropriate $576 million -- the FY 1987 authorization level for the ADMS block grant. The federal leadership which identified alcohol and drug dependent women as a special population in need of increased services must be coupled with a significant fiscal commitment if states are to be responsive to this federal mandate while providing adequate public treatment and prevention services to all individuals in need.

The National Council on Alcoholism joins a host of other alcohol, drug abuse and mental health organizations in our support of the appropriations levels for NIAAA research and the ADMS block grant outlined in this testimony. Our deliberations over recommended funding levels were informed by a recognition of the budgetary constraints facing the Congress at this time. However, NIAAA funded research has categorically proven that the price of treating the alcoholic is far less costly to the government and the community at large than the price of leaving the alcoholic untreated. Research and clinical studies have also clearly shown that early intervention holds greater promise for recovery. Research investigations which suggest a correlation between early onset of alcohol use and a likelihood to experience alcohol related problems hold great import for prevention and education strategies aimed at delaying the age of onset. Our knowledge about alcoholism and alcohol-related problems has grown a hundred fold over the last decade. Federally funded research has offered new insight as well as new directions for further study and aggressive action. We now face the opportunity and challenge of dramatically reducing the toll of alcoholism and alcohol-related problems in our lifetime. A robust alcohol research and prevention effort and a comprehensive public treatment system are certainly key elements to meeting that challenge.

NATIONAL COUNCIL ON ALCOHOLISM INC

FACTS ON ALCOHOLISM AND ALCOHOL-RELATED PROBLEMS

☐ **Alcoholism is a chronic, progressive and potentially fatal disease characterized by tolerance and physical dependency or pathologic organ changes, or both.** All are the direct or indirect consequences of the alcohol ingested. (National Institute on Alcohol Abuse and Alcoholism (NIAAA). **Fourth Special Report to the U.S. Congress on Alcohol and Health**, ed. John R. DeLuca. DHHS Pub. No. (ADM) 82-1080. 1981. p. 36.)

☐ **Alcoholism and alcohol abuse occur in every socio-economic group, although the problems may manifest themselves differently across groups.** (Congress of the United States, Office of Technology Assessment, Health Technology Case Study 22. **The Effectiveness and Costs of Alcoholism Treatment**, prepared by Leonard Saxe, Ph.D., et al., OTA-HCS-22. 1983. p 3.)

☐ **Alcoholism is one of the most serious public health problems in the United States today.** Among the 18.3 million adult "heavier drinkers" (those consuming more than 14 drinks per week) 12.1 million have one or more symptoms of alcoholism, an increase of 8.2 percent since 1980. (NIAAA, Department of Biometry and Epidemiology. 1985. **Working Paper: Projections of Alcohol Abusers, 1980, 1985, 1990**, prepared by John Noble. pp. 5 and 6.)

☐ **Alcohol is the most widely used—and abused—drug in America.** In 1981, the equivalent of 2.77 gallons of absolute alcohol was sold per person over age 14. This is about 591 12-ounce cans of beer, 115 fifths of table wine or 35 fifths of 80 proof whisky, gin or vodka. A tenth of the drinking population consumes half the alcoholic beverages sold. (NIAAA, **Fifth Special Report to the U.S. Congress on Alcohol and Health**, from the Secretary of Health and Human Services. DHHS Publication No. (ADM) 84-1291. 1983. p. xii.)

☐ **Alcohol abuse accounts for approximately 98,000 deaths annually.** This includes cirrhosis and other medical consequences, alcohol-related motor vehicle accidents and alcohol-related homicides, suicides and non-motor vehicle accidents. (R.T. Ravenholt, M.D., **Addiction Mortality in the U.S.**, National Institute on Drug Abuse (NIDA), March 1983.)

☐ **$116.7 billion was the economic cost to the nation resulting from alcohol abuse and alcoholism in 1983.** The economic impact in 1980 (current dollars) was $89.5 billion. (Research Triangle Institute (RTI). **Economic Costs to Society of Alcohol and Drug Abuse and Mental Illness: 1980**. Henrick J. Harwood, et al., June 1984. pp. G-16 and 7.)

☐ **Alcoholism treatment reduces total health care costs.** In a study of over 20 million claim records between 1980 and 1983, alcoholic families used health care services and incurred costs at twice the rate of similar families with no known alcoholic members. The average alcoholic's treatment cost was offset by reductions in other health care costs within 2 to 3 years following the start of treatment. (NIAAA, **Alcoholism Treatment Impact on Total Health Care Utilization and Costs**. U.S. Dept. of Health and Human Services. February 1985. pp. 1, 3.)

☐ **Alcohol is known to cause or contribute to other fatal illnesses, including cardiac myopathy, hypertensive diseases, pneumonia and several types of cancer.** (Ravenholt, **Addiction Mortality**, NIDA, March 1983.)

☐ **One out of three American adults—56 million Americans—say that alcohol abuse has brought trouble to their families.** This is about four times the number of families that say that other drugs have troubled their homes. (P. Regans, **ABC News/Washington Post Poll**, Survey #0190, May 1985.)

☐ **Chronic brain injury caused by alcohol is second only to Alzheimer's disease as a known cause of mental deterioration in adults.** Alcoholic mental deterioration is not progressive. If the patient stops drinking, the deterioration is arrested and substantial recovery can occur. (NIAAA, **Fifth Special Report**, p. xv.)

☐ **Children of alcoholics have a four times greater risk of developing alcoholism than children of non-alcoholics.** There are 28.6 million children of alcoholics in the U.S. today, 6.6 million of whom are under the age of 18. (Children of Alcoholics Foundation, **Children of Alcoholics: A Review of the Literature**, 1985. Introduction and p. 2.)

☐ **Genetic influence is identifiable in at least 35 to 40 percent of alcoholics and alcohol abusers, and it affects both men and women.** People with family histories involving parental alcohol abuse face increased risk. Furthermore, many types of alcohol abuse may exist, each with its own genetic predisposition interacting with a particular environment. (NIAAA, **Fifth Special Report**, p. 22.)

☐ **An estimated 3.3 million drinking teenagers aged 14 to 17 are showing signs that they may develop serious alcohol-related problems.** (NIAAA, **Third Special Report to the U.S. Congress on Alcohol and Health**, 1978, p. 14.)

☐ **Recent surveys conducted in the United States indicate that the first drinking experience today usually occurs around age 12, in contrast to ages 13–14 in the 1940s and 1950s.** It is no longer unusual for 10–12-year-olds to have serious alcohol abuse problems. (Nancy P. Gordon and Alfred McAlister, "Adolescent Drinking: Issues and Research," in **Promoting Adolescent Health** (New York: Academic Press, 1982), pp. 201, 203, 210. David W. Brook and Judith S. Brook, "Adolescent Alcohol Use," Editorial, **Alcohol and Alcoholism**, Vol. 20, No. 3 (Great Britain, 1985), p. 259.)

☐ **Since 1966, the number of high school students nationwide intoxicated at least once a month has more than doubled, from 10 percent to more than 20 percent.** (Dorothy G. Singer, "Alcohol, Television and Teenagers," **Sex, Drugs, Rock 'N' Roll**, Yale University Family Television Research Consultation Center (New Haven: 1985), pp. 668, 671.)

☐ **Most youth begin to drink in adolescence.** A recent study on adolescent alcohol abuse relevant to prevention efforts found that alcohol is the most widely used drug by youth between the ages of 12 and 17. (NIAAA, **Fifth Special Report**, p. 125.)

☐ **About 30 percent of fourth grade respondents to a 1983 "Weekly Reader" poll reported peer pressure to drink beer, wine or liquor.** (Weekly Reader Publications, **A Study of Children's Attitudes and Perceptions about Drugs and Alcohol**, conducted by the Weekly Reader, Xerox Education Publications, 1983, Table 2.)

☐ **Of 27,000 New York public school students, grades 7 through 12, 11 percent described themselves as being "hooked" on alcohol.** (New York State Division of Alcoholism and Alcohol Abuse, **Drug and Alcohol Survey**, 1983.)

☐ **By ninth grade, more than half (56 percent) of high school seniors responding to a 1982 national survey had tried alcohol.** By their senior year, more than 9 out of 10 had done so. (NIAAA, **Fifth Special Report**, p. xiii.)

☐ **Fetal Alcohol Syndrome (FAS) is the third leading cause of birth defects with accompanying mental retardation, and the only preventable one among the top three.** The incidence of FAS is approximately 1 in 750 live births, or 4,800 babies per year in recent years. Thirty-six thousand newborns each year may be affected by a range of less severe alcohol-related fetal alcohol effects (FAE). (RTI, **Economic Costs to Society**, p. B-3.)

☐ **Women frequently engage in the high risk practice of abusing other drugs in combination with alcohol.** In a 1983 Alcoholics Anonymous Survey, 40 percent of female A.A. members reported addiction to another drug. The number increased to 64 percent for women 30 years and under. (General Service Office of Alcoholics Anonymous, Inc., **Membership Survey**, 1983.)

☐ **In 1984 there were 44,241 highway deaths, of which 23,500 (53 percent) were alcohol-related.** (National Highway Traffic Safety Administration, **Alcohol in Fatally Injured Drivers—1984**, Washington, D.C.)

☐ **About 65 out of every 100 persons in the U.S. will be in an alcohol-related crash in their lifetimes.** (National Highway Traffic Safety Administration, U.S. Dept. of Transportation, **Drunk Driving Facts**, National Center for Statistics and Analysis, June 1984.)

☐ **Alcohol-related highway deaths are the number one killer of 15–24-year-olds.** (Health, United States, 1980, National Center for Health Statistics, Public Health Service, U.S. DHHS Pub. No. (PHS) 81-1232, December 1980.)

☐ **Alcohol is a contributing factor in at least 15,000 fatal and six million nonfatal injuries in non-highway settings.** (NIAAA, **Alcohol Health and Research World**, Summer 1985, Vol. 9, No. 4, p. 25.)

☐ **Between 400 and 800 boating fatalities annually involve alcohol.** Alcohol is implicated in from 65 to 69 percent of all reported drownings. (NIAAA, **Alcohol Health and Research World**, Summer 1985, p. 28.)

☐ **Alcoholics are 10 times more likely to die from fires than non-alcoholics, 5 to 13 times more likely to die from falls, and commit suicide from 6 to 15 times more frequently than the general population.** (NIAAA, **Fifth Special Report**, pp. xix and xx.)

☐ **Drinking is estimated to be involved in about 50 percent of spouse abuse cases and up to 38 percent of child abuse cases.** (NIAAA, **Fifth Special Report**, p. xx.)

☐ **Fifty-four percent of jail inmates convicted of violent crimes were drinking before they committed the offense.** Sixty-two percent of those convicted of assault had been drinking. Forty-nine percent of those convicted of murder or attempted murder had been drinking. (Bureau of Justice, **Statistics Survey**, 1983.)

☐ **Between 2 and 10 percent of people 65 and over experience some type of alcohol-related problem. Approximately 25 percent of the 65-plus population is on some form of medication. By most measures, older people consume more medication than any other age group, putting them at high risk for drug and alcohol interaction. (NIAAA, Alcohol Health and Research World, Spring 1984, Vol. 8, No. 3, pp. 4 and 6.)**

Founded in 1944, NCA is the nation's nonprofit voluntary health organization established to prevent and reduce problems of alcohol abuse and alcoholism. NCA's network of 184 state and local affiliates conduct similar activities in their areas and provide information and referral services to families and individuals with a drinking problem.

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Mr. NATCHER. Thank you very much. You have made an excellent statement. We appreciate your appearance before the committee.

The committee will now recess until 2:00 this afternoon.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

DR. MELVIN SABSHIN, MEDICAL DIRECTOR, AMERICAN PSYCHIATRIC ASSOCIATION

Mr. NATCHER. Our first witness this afternoon is Dr. Melvin Sabshin. Come around, Doctor. It will be a pleasure for us to hear you today. You have been before our committee on a number of occasions, and we are always glad to have you.

Dr. SABSHIN. I am pleased to have the opportunity to be back here before your subcommittee. This time, I am testifying regarding the President's proposals for fiscal year 1987 appropriations for ADAMHA.

I am here representing the American Psychiatric Association and its 32,000 members, and also representing groups that are involved with academic institutions and training programs in our field, and some other subspecialty groups.

Also, I am pleased to say that I am here as part of a coalition of 45 organizations in the mental health field, and these groups are more united than ever before in offering budgetary alternative recommendations.

Also, part of an Ad Hoc Group for Medical Research Funding, 200 groups involved in support of the ADAMHA recommendations.

Mr. Chairman, this new unity of approach is one that is very important for us, and we have a strong coalition that includes professionals and consumers in recommending the budgetary allocations.

May I ask you to insert our testimony and the statement of the coalition into the record, and I will comment on just a few?

First, I want to express my thanks to you and the subcommittee. You have paid close attention to the mental health needs. You have demonstrated sophisticated knowledge and strong support.

I regret to say that once again, the President's recommendations call for a reduction in dollars for the agency, and in effect, call for a loss of momentum, and I want to stress that theme of momentum in the ADAMHA support.

The President recommends 348,000,000 for fiscal year 1987, contrasted with $366,000,000 allocated in fiscal year 1986, prior to the Gramm-Rudman sequestration.

The dollars recommended by the President are significantly lower than the $406,000,000 necessary to continue at the 1986 level and dramatically below the IOM recommendation of 465,000,000.

I am here representing a field that shows marvelous momentum, strong new developments in research, strong new developments in treatment, styles and approaches, and in just the last two years, the development of new medications for the treatment of manic-depressive illness, to go beyond the effects of lithium affords enormous progress for us.

The research has better epidemiology, which is good for scientific value, for you, sir, this subcommittee, to see the high and low incidence of mental illnesses and in terms of public policy, that type of research is very useful.

There has been a clarification of objectives and priorities and these developments have received worldwide a claim, and I am proud of the United States in that regard, but they come at a point when the economic constraints are in a situation that we are all concerned about, where they can produce a short-sighted take away of our momentum.

That is what I am distressed about in terms of the President's recommendation.

23 percent or so of the population is involved with the decisions that you will make, and 2,000,000 children, 10 percent of the citizens over 65, we are dealing with a problem that is at least equivalent to that of cancer, but the residues of the stigmata and negative attitudes continue to pose problems in funding.

100 times as much as allocated for cancer research as is allocated for patients with mental illness, and the problems in terms of frequency are essentially equivalent.

I only wish to focus on six issues very briefly. First, I want to state our hopeful do what you can to protect the research centers. These are programs which have the critical mass of personnel and the longevity of support, so they can accomplish the national goals by providing first-class research for us.

I hope we can keep the momentum and support for the research scientific development awards. I hope you will give serious consideration to a new but significant number of new and competing grants.

I ask you once again to preserve a small nucleus of clinical training grants, and especially for fiscal year 1987, to pay attention to the underserved population, to new partnerships between State programs and academic institutions for training as, for example, on a special emphasis on education.

I hope there will be a modest continuation of basic community support programs. There is a need for continued Federal involvement in these areas, and I hope you will provide a sufficient staff for the ADAMHA agencies so they can carry on cost-effective administration of these agencies.

Mr. Chairman, I believe that there are strong scientific and economic reasons for keeping the momentum that you have helped so well in the past, and I ask for this modest support which I believe will serve our Nation well, and I ask for your serious consideration of the amounts that have been requested.

Thank you, sir.

Mr. NATCHER. Thank you very much, sir.

[The statement of Dr. Sabshin follows:]

American Psychiatric Association

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STATEMENT

OF THE

AMERICAN PSYCHIATRIC ASSOCIATION

AMERICAN ASSOCIATION OF CHAIRMEN OF DEPARTMENTS OF PSYCHIATRY

AMERICAN SOCIETY FOR ADOLESCENT PSYCHIATRY

AMERICAN ASSOCIATION OF DIRECTORS OF PSYCHIATRIC RESIDENCY TRAINING

ON THE

FISCAL YEAR 1987 APPROPRIATIONS

FOR THE

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

PRESENTED BY

MELVIN SABSHIN, M.D.
MEDICAL DIRECTOR
AMERICAN PSYCHIATRIC ASSOCIATION

BEFORE THE

COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR,
HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

U.S. HOUSE OF REPRESENTATIVES

MAY 1, 1986

Mr. Chairman and Members of the Subcommittee, I am Dr. Melvin Sabshin, Medical Director of the American Psychiatric Association, a medical specialty society of over 32,000 psychiatrists nationwide. I am testifying not only to express the particular concerns of the American Psychiatric Association regarding the President's proposed FY 1987 appropriations for the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), but also those of the American Association of Chairmen of Departments of Psychiatry, the American Association of Directors of Psychiatric Residency Training, and the American Society for Adolescent Psychiatry. I also speak on behalf of a coalition of over 45 constituent organizations in the mental health and substance abuse community that have united in offering an alternative ADAMHA budget -- which is also endorsed by the Ad Hoc Group for Medical Research Funding, a diverse group of almost 200 organizations united by their concern about biomedical and behavioral research. I ask permission to insert the coalition's statement into the hearing record. A one page summary of our substitute ADAMHA budget proposal is attached.

RESEARCH/
RESEARCH TRAINING

Over 90 percent of research on mental and addictive disorders is dependent on federal funding. As you know, the ADAMHA research mission covers a large and diverse range of people with an overall prevalence of mental and addictive disorders for all age groups in the United States in the range of 15 to 22.5 percent. Thus, ADAMHA supported-research is of direct relevance to 30-45 million Americans, including over 2 million children with serious mental disorders and at least 10 percent of our citizens who are over 65 years of age. To appreciate the magnitude of the problem as contrasted to funding support only 5 to 6 million Americans have been treated for cancer at some time. For every patient treated for cancer, more than $300 is spent on research; for schizophrenia the sum is $7. Overall, yearly expenses for mental and addictive disorders total an estimated $185 billion in 1980 (IOM Report). By 1983 that number had risen to $218 billion.

The President's proposal for ADAMHA research and research training totals $348 million in FY '87, a reduction from the comparable level of $366 million in FY '86 (prior to the Gramm-Rudman triggered sequestration of funds). Of this reduced amount, an additional $9 million, in AIDS-related research dollars, is proposed to be taken away and transfered to the office of the Assistant Secretary for Health. This $348 million level -- without regard to the further effective reduction of $9 million -- falls far short of the "no-growth" or "current services" benchmark level of $406 million (i.e. the amount that is needed to continue with adjustments for inflation the same level of activity in FY '87 as in FY '86) and is dramatically below the professional judgment recommendation of the Institute of Medicine of $465 million.

The cornerstone of the 1987 budget for both ADAMHA and NIH research is a new "stabilization policy" based on the total numbers of grants supported by each agency. Without regard to the merit of this methodology, for ADAMHA the OMB number is far too low -- 1400 total research project grants. Because 930 are reserved for continuation support to present investigators, the budget would necessitate a dramatic reduction ih the number of supportable new and competing research projects from 550 under the 1986 appropriation to only 448, effectively undermining the opinion of key science advisors. Instead of maintaining a stable and predictable level of competition among scientists for already constrained research support, scientists under this proposal would again face a wild downward spiral in the availability of research support, making funding dependent more upon the timing of applications than on quality and merit. The proposed budget also imposes equally arbitrary and unnatural patterns of research support by emphasizing a fixed number of project grants at the expense of other mechanisms such as clinical research centers.

Adoption of the President's budget would specifically:

- Allow NIAAA to fund only 74 new and competing grants, 26 fewer than the level appropriated by Congress in FY 1985 and 1986; and require 16% cuts in the average costs of new and competing awards;
- Reduce the number of NIMH new and competing research grants to 257, 62 fewer than Congress authorized in 1986;
- Drop the number of new and competing grants at NIDA from 131 to 117;
- Prohibit the award of any new and competing grants for NIMH clinical research centers dedicated to basic research, studies of childhood disorders, the mental health of the elderly, major psychoses, the genetic bases of mental disorders, and prevention; six highly productive centers currently supported by NIMH funds could not be renewed.
- Reduce the total number of NIMH research trainees to 751 (a reduction of nearly 50% over six years); further reduce the already insufficient number of research trainees at NIAAA and NIDA to 63 and 68, respectively.
- Slash by one-third the number of Research Career Development Awards and small grants which were authorized by Congress in 1986. These programs are essential in attracting and maintaining a cadre of highly talented young researchers in the field.

We appreciate the Subcommittee questions to the Administration witnesses which for the first time made public that there exists a potentially critical budget shortfall in the NIMH Research Centers mechanism in which funding for six competing/renewal centers is eliminated. The typical MHCRC grant provides core facilities to support several research projects with the aim of providing research environments where multidisciplinary teams of investigators can interact and develop focused programs of research on mental disorders, including those affecting children and the elderly. We are grateful for your interest and urge your Subcommittee to act prudently and reject this ill-advised proposal.

These reductions I have outlined are damaging in themselves, but even more so when held up to the light of the present burgeoning opportunities for improved, cost effective treatments. We feel that an explosion of research on the brain, one of the last frontiers of medical science, will offer eventual cures for some of today's most feared disorders. The recent research track record justifies our confidence. In the conduct of research into mental illness, alcoholism and drug abuse, ADAMHA-supported research has already, to name only a few:

- Demonstrated that the anti-convulsant Tegretol is effective in treating and preventing episodes of manic depressive illness, important both because it is particularly effective in people unable to tolerate or otherwise unable to utilize lithium and because it has opened up the potential similarity of psychobiological mechanisms surrounding manic depression and seizure disorders. Earlier estimates of the cost savings as the result of the introduction of lithium (approximately $6.5 billion in the past decade) can be expected to increase 20-50% with the addition of this drug to the arsenal of psychotropic medications.
- Confirmed that heredity is a major contributing cause of alcoholism in a substantial proportion of cases and provided clues to the physiological and molecular basis of the genetic predisposition to alcoholism.
- Identified and studied the consequences of drug use, including the effects of drugs on fetal development, motivation and emotion, personality and cognitive abilities, and performance, as well as the consequences of cessation of chronic drug use.
- Identified the precise, sub-cellular biochemical changes in the nervous systems of animals during

learning and the formation of memory, both major components of all complex behavior. The significance of this discovery earned the Lasker Award and other major scientific prizes.

- Uncovered the strong link between alcohol and harm to the human fetus; and further found that even if a mother receives a nutritionally adequate diet, alcohol interferes with the transport of nutrients across the placenta, causing malnutrition in th fetus.
- Demonstrated that the use of alcohol damages the central nervous system at an earlier point in its use and that the damage is not as localized as previously had been thought.
- Developed behavioral interventions that reduce the incidence of delinquency among high-risk children and youth;

The unique questions that ADAMHA Institutes ask about brain function and behavior argue for their continuing to be a major source of support for research in both the neurosciences and in the psychosocial sciences, because progress within one discipline in the biobehavioral sciences often is intertwined closely with advances in others. For example, the discovery of effective drug treatments for several major mental disorders was a strong stimulus for basic research on brain physiology, pharmacology, and biochemistry and for improved diagnostic and clinical procedures to assess drug effects. The fact that available drugs do not work for everyone and that they have unpleasant, sometimes dangerous side effects has fostered, in turn, a search for safer, more effective drugs and has encouraged consideration of psychological and social treatments that can be used alone or in combination with an appropriate drug. Investigators using the tools of epidemiology have identified different forms of mental disorders and patterns of drug and alcohol use and abuse among different subpopulations in this country and in other cultures. These data are needed to improve diagnostic reliability and validity and to develop more individually tailored treatment interventions.

Mr. Chairman, the Ad Hoc Group for Medical Research Funding this year joins with us in urging Congress to appropriate a major infusion of new research dollars into areas within the ADAMHA purview. The group's recommendation documents the historical ADAMHA shortfall stating, "this increase is necessary to achieve catch-up growth in funding of mental health and addictive research . . . and restores ADAMHA purchasing power for research and research training to the constant dollar level of 1974."

The alternative proposal of APA, the Ad Hoc Group and others does not seek to play a "numbers game" as proposed by the President. Rather, this proposal is based on the present scientific opportunities in the field and the importance of the research that can be done. Specifically, it would:

- Permit support of 425 new and competing NIMH regular research grants, 168 more than the number which would be supported under the President's proposal;
- Permit NIAAA to award 116 new and competing investigator-initiated project grants at IRG-recommended levels; an increase of 16 percent over the number awarded in FY 1986;
- Allow NIDA to add 16 new and competing grants above the FY 1986 level of 100 awarded, including the funding for 3 major grants to support large clinical and treatment research projects;
- Enhance dramatically NIMH's ability to support university-based Research Centers: continuation levels would be restored to the levels approved by the NAMH Council; the six competing renewals otherwise lost in FY 1987 would be continued; and three new Centers (focusing on schizophrenia, childhood disorders; and mental health of the elderly) would be funded, as would two Centers investigating AIDS-related mental health issues;
- Augment the Research Scientist Development Award program -- with special emphasis on talented, young clinical researchers, to ensure the future availability of well-trained personnel;

- Increase the number of research trainees supported by NIMH from 751 permissible under the President's budget to 1200, and expand the number of research trainees at NIDA and NIAAA to 100 and 80 respectively -- a significant step toward the 1500 trainees recommended by IOM;
- Ensure adequate personnel and equipment for the Intramural Research Programs of all three ADAMHA Institutes.

What lesson is the Administration with its budget proposals teaching to those suffering from mental or substance abuse disorders? What lesson is taught those young physicians and others considering a career in research into these illnesses? For the former, it is a reaffirmation of the stigma attached to mental illness or addictive disorders. For the latter, it is a confirmation that the Nation's research commitment is a vicious cycle of diminished financial resources leading to diminished interest and involvement, resulting in tremendous potential loss to society as a whole.

If the Nation fails to invest wisely in efforts to reduce the costs of mental illness and addictive disorders, we all will continue to pay the price in increased hospital care, increased secondary illness, lost productivity and, ultimately, lost lives. We are confident, Mr. Chairman, that with your support enhanced funding of ADAMHA research will yield dividends.

CLINICAL TRAINING

The Administration's FY-1987 budget again proposes to eliminate all federal support for Clinical Training activities. According to the Institute of Medicine (IOM) report "Research on Mental Illness and Addictive Disorders," 15% of the population suffers from serious mental disorders at any given time, but less than one-third of these people will receive any form of treatment. The magnitude of the problem indicates that this is clearly a matter of national concern that cannot be adequately addressed at the state and local level. Training professionals to meet these needs is a long-recognized federal concern, especially in view of unanimous evidence that certain populations and geographic areas are underserved, including enormous numbers of senior citizens, children, jailed populations and chronically mentally ill living in the community.

In recent years I have brought to your attention the outstanding results of NIMH-supported projects linking academic training centers and understaffed state service facilities in psychiatric training. For example, one-third of all state hospital psychiatrists in Maryland are products of this program. The NIMH should be permitted to strengthen this priority for closer coordination between training centers and seriously understaffed public mental health settings. We are disturbed to see that the psychiatry training branch bears a disproportionate share of the $2 million reduction from FY 1985 to FY 1986 and restate that federal support for institutional teaching costs is an effective investment in assuring that psychiatric trainees provide direct clinical services to Congressionally specified underserved populations. Accordingly, we join with the ADM coalition in asking Congress for $26 million for NIMH Clinical Training. We also request a minimal $2 million appropriation for grants to support the training of health professionals in the identification and treatment of alcohol and drug abuse problems. An adequate pool of alcohol and drug abuse program personnel has not developed as neither the States nor the private sector have assumed responsibility for the funding of training programs. In fact, many training programs have been dismantled at a time when the need for more competent drug and alcohol abuse personnel is being clearly demonstrated.

SERVICES

Considering the impact of inflation since 1985 the President's request for the ADAMHA Block Grant of $490 million would result in a decrease of $39.0 million in the purchasing power for existing services. This budget would not allow states to respond to the crisis of the large and growing number of people with chronic mental illness who are homeless, nor meet the demand for alcohol and drug abuse services by the general public, DWI offenders, cocaine addicts and IV drug users who have been alerted to the spreading threat of AIDS among the IV populations. We recommend an appropriation of $576.0 million for the ADAMHA Block Grant and $5 million for the state interagency planning grants.

The President's request provides no funds for the Community Support Program in FY 1987 and would wipe out this small but effective initiative. Failure to fund CSP demonstration projects will severely curtail the ability of states to better and more cost effectively serve deinstitutionalized adults, homeless people with chronic mental illness, children and adolescents with severe emotional problems, and individuals with chronic mental illness -- people who otherwise move in and out of the hospital and into the more costly criminal justice and jail systems. The number of applications to NIMH continues to exceed available resources. We recommend $20 million for the Community Support Program and other service demonstrations for FY 1987.

STAFFING

Curtailment of essential travel, publications, and communications expenses can result in the waste or misdirection of tens of millions of dollars. ADAMHA must maintain stewardship and oversight over the expenditure of its funds, (e.g. restore the AIDS research program to ADAMHA); provide opportunities for its own staff to stay in touch with new developments in the field; (e.g. needed funds for NIMH site visitation and technical assistance to extramural research grantees) and have the ability to disseminate the results of its work (e.g. to NIDA for prevention and communications activities and to NIAAA for the National Clearinghouse for Alcohol Information, and high-priority Homeless, Prevention and AIDS-related activities. This program is proposed for transfer to the PHS under the 1987 budget).

Mr. Chairman, we feel that this proposal which I have outlined today is both scientifically and politically justifiable and stand ready to assist the Congress in the development of a responsible alternative to the President's proposal.

APA SUBSTITUTE ADAMHA BUDGET COMPARATIVE

(in $ millions)

	FY '86 Congressional Appropriation	FY '87 Current Services	FY '87 President's Budget	FY '87 Our Proposal
Research				
(NIMH)	214.0	237.0	199.0	272.0
(NIDA)	74.0	82.6	73.0	90.5
(NIAAA)	57.0	63.7	56.6	72.0
Research Training	21.0	22.7	18.5	31.3
Clinical Training				
(NIMH)	19.0	20.0	0	26.0
(NIDA)/(NIAAA)	1.0	1.0	0	2.0
Block Grant	490.0	525.0	490.0	576.0
State Planning	0	0	0	5.0
Community Support	12.5	11.0	0	20.0
Protection/ Advocacy	10.0	10.5	0	10.5
Direct Operations	62.5	63.0	58.5	65.6

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESSES

DR. ROGER E. MEYER, AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

FREDERICK H. GRAEFE, COUNSEL

Mr. NATCHER. Our next witness is Dr. Meyer. Come around, Doctor.

Dr. MEYER. I am testifying today as last year on behalf of the American College of Neuropsychopharmacology, a distinguished organization of 430 members from all relevant disciplines concerned about biological function, in the CNS and its relationship to the causes and treatment of mental and addictive disorders; and CPDD, an organization concerned with the application of scientific findings to public policy in the field of substance abuse.

I am accompanied by Mr. Graefe, as I was last year.

I have a capsule summary of some research reports that have appeared over the past year since I testified before your committee.

They highlight how ADAMHA supported research has provided new windows on brain function that are demonstrating the relationship between specific mental dysfunctions and brain abnormalities.

I hope that you also had the opportunity to read the recent series on schizophrenia that appeared in the New York Times.

This series served to highlight the extreme personal, familial and societal costs of this disorder; the limited resources that have been made available for community care and rehabilitation; and the tremendous promise of research.

My testimony also highlights the application of recent research findings to the treatment of panic disorder, with consequent improved patient care at reduced costs of diagnosis and treatment.

Two, like other witnesses before this committee, I am concerned about the effects of Gramm-Rudman-Hollings on the future of biomedical research. The President's budget proposal for ADAMHA represented a 7.9-percent cut from fiscal year 1986.

The Ad Hoc Group for Medical Research Funding has proposed an alternative budget of $434,500,000: $272,000,000 at NIH; $72,000,000 at NIAAA and $90,500,000 at NIDA. The 1984 recommendations of IOM, $500,000,000.

President's budget cuts new and competing grants at NIAAA and NIMH by 25 percent; 12 percent at NIDA. Impact on NIMH centers, NIDA centers.

The President's budget would dismantle those centers whose turn happened to come up in the review cycle. This is not science policy based upon a critical review of excellence; it is more akin to Russian roulette.

Three, the essential interconnectedness of research support: Individual research grants, research centers, research training for new investigators, support for equipment and support for intramural research at the three Institutes.

Issues include numbers of RO-1s as a means of stabilization; problems include clinical research and the effects on staff-initiated cuts and effect on equipment.

Issues include centers as importance of mission-based interdisciplinary teams to the advancement of science, in industry and in university settings.

The President's budget supports a 16-percent increase in support for research, but not in the life sciences where he proposes significant cuts from 1986. This will impact on the present and on the future, such as where young investigators will choose to go.

Lastly, I would like to invite you and members of the staff to join with the ACNP and representatives of citizens groups this December, when ACNP celebrates its 25th anniversary.

We hope you will be able to attend the meetings and share in the pride in terms of what this Congress has helped to build in terms of biomedical research.

Gramm-Rudman calls for deficit reduction, not for dismantling the biomedical research of this country. There are ways to reduce the deficit and strengthen the biomedical research. We hope for your continuing support.

[The statement of Dr. Meyer follows:]

TESTIMONY

OF

ROGER E. MEYER, M.D.

ON BEHALF OF THE AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

AND

THE COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

BEFORE THE SUBCOMMITTEE ON LABOR, HEALTH

AND HUMAN SERVICES AND EDUCATION

HOUSE COMMITTEE ON APPROPRIATIONS

MAY 1, 1986

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My name is Dr. Roger E. Meyer. I am Professor and Chairman of the Department of Psychiatry and Scientific Director of the Alcoholism Research Center at the University of Connecticut School of Medicine. I am speaking today on behalf of two organizations who share a concern about the future of research on alcoholism, drug abuse, and the multiple forms of mental disorder. The Committee on Problems of Drug Dependence is a distinguished multidisciplinary panel that has been established under the general sponsorship of ten professional societies. For more than 30 years the committee was previously part of the National Academy of Sciences/National Research Council. It continues to advise relevant governmental and international organizations on the abuse liability and scheduling of drugs, and to sponsor the major annual scientific meeting in the field of drug abuse. The committee, therefore, has generic responsibility for encouraging scientific communication through its annual meeting and the publication of its annual monograph; and for expediting the application of scientific findings to public policy in the field of drug abuse.

The American College of Neuropsychopharmacology is an organization of more than 430 members from all relevant disciplines concerned about biological functionin the central nervous system, and its relationship to the causes and treatment of mental and addictive disorders. The ACNP membership represents the most significant group of scientists involved in this kind of research in the United States. This December, in Washington, the ACNP will be celebrating its 25th anniversay as an organization. The site and the timing are rich with symbolic meaning. Washington was the place where ACNP first met, when new drugs appeared to offer the first real hope ever for the mentally ill. It was Congress (in this city) which specifically mandated that NIMH conduct research in psychopharmacology, and it has been Congress which has authorized the funding over these years which has supported the research that has described the mechanism of action of many of these compounds; their real benefits and unfortunate limitations. As you know, it was easier for Congress in those times to authorize and appropriate funds for biomedical research than in the present decade. Indeed, even as this committee has moved to support equivalence between ADAMHA and NIH, Gramm/Rudman/Hollings poses a significant threat to both biomedical research support agencies.

ADAMHA-supported research has provided important new windows on brain function that, for the first time, demonstrate the relationship between specific mental dysfunction and brain abnormalities.

°Pet Scan Technology

Utilizing positron emission tomography (the PET scan), researchers at Washington University School of Medicine have found that patients with panic disorder who were untreated demonstrated increased metabolic activity at the right para hippocampal gyrus. Previous research had demonstrated that these episodes could be regularly triggered by lactate infusion. Appropriate pharmacological treatment of the panic disorder effectively prevents panic attack and its biological dimensions during lactate infusion.

°Studies of Regional Central Blood Flow

Researchers at the National Institute of Mental Health Intramural Research Programs at St. Elizabeth's Hospital here in Washington utilized regional cerebral blood flow technology to evaluate brain physiology and mental function simultaneously in medication-free patients with chronic schizophrenia, patients treated with standard neuroleptic drugs, and normal controls. One of the persistent deficits in schizophrenia involves difficulties with abstracting ability. The investigators at NIMH, using a standard psychological test of abstraction, demonstrated that both medicated and unmedicated chronic schizophrenic patients showed a paucity in dorso lateral prefrontal cortical activity (compared with control subjects) -- under conditions when all subjects were performing the same test of abstracting ability. This new approach to simultaneous examination of brain function and cognitive ability may help to clarify aspects of schizophrenia, potential risk factors in family members of patients, as well as potential new approaches to some of the treatment resistant aspects of the disorder.

•Imaging Studies in Alcoholics

Researchers at the National Institute on Alcohol Abuse and Alcoholism have been using the PET scan to delineate pathological brain function associated with alcoholism. Intramural researchers at NIAAA hope to access the new magnetic resonance imaging technology to clarify aspects of brain function in alcoholics, as well as children at risk for development of alcoholism. As you may know, researchers at Downstate Medical Center in New York and at the University of Connecticut have demonstrated electrophysiological abnormalities in children of alcoholics which may constitute a potential marker for alcoholism. Longitudinal research with these children, and the application of other technologies of assessment such as MRI, will be critical in the coming year.

Researchers supported by the National Institute on Drug Abuse are also involved in efforts to define risk factors in populations of individuals who seem to be at great potential for subsequent problems with substance abuse. Epidemiological studies supported by NIDA suggest that certain behavioral problems already manifest in the first grade in school were highly predictive of drug abuse in an inner city population. Children who did not demonstrate these behavioral abnormalities in the classroom were unlikely to be drug abusers in late adolescence and young adult life. Research conducted by a child psychiatrist at the New York University Medical Center has suggested that a substantial proportion of children with conduct disorder have abnormalities of cognitive function that are suggestive of deficits in brain physiology. The new imaging technologies utilizing cerebral blood flow, positron emitting tomography, and magnetic resonance imaging, in the context of methodology drawn from epidemiology, population genetics and the behavioral and social sciences, should help to clarify the relationship between brain function and individual risk.

The aforementioned research represents only a very small capsule of ADAMHA-supported programs, their current excitement and extraordinary potential. The various reports have appeared in the 12 months since I last came before your committee. A recent series on schizophrenia in the New York Times has served to highlight the extreme personal, familial, and societal costs of this disorder; the limited resources that have been made available for community care and rehabilitation; and the tremendous promise of research. The ADAMHA portfolio is necessarily interdisciplinary, and includes research in the psychological and social sciences, epidemiology, and of course neurobiology. Treatment outcome studies have identified the critical synergestic effects of medications and other forms of therapy for certain disorders.

What emerges from all this is that as research delineates problems more precisely, clinical practice can become more effective and costs can diminish. In the not so distant past, many patients with panic disorder were subject to expensive cardiovascular workups because of the non-specific cardiac nature of their complaints. After their workup by the internist, the patients would generally be referred to a psychiatrist for non-specific long-term psychotherapy. It is now clear that patients with true panic disorder are best treated with medication, while behavioral and other psychotherapy should focus on simple phobias and other concomitants of the disorder. That medication alone is effective in the vast majority of patients has had tremendous implications on the health care costs of this disorder, as well as the social costs of lost productivity. Parenthetically, untreated panic disorder also serves as a risk factor for alcohol and other drug abuse for some individuals.

This review of some of the research news of the past year was meant to highlight the real progress that is being made with the funds that have been made available to ADAMHA research. It is not easy for a political body, which represents the body politic, to support programs of research which promise non-specific future benefit -- in the face of current urgent realities. The budget deficit _is_ real. It has grown more urgent during the past five-and-a-half years than at any time in our history. By radio, the people are told that the fault lies with the Congress. But even David Stockman himself has begun to set the record straight; that it is Congress that has shown the wisdom to differentiate appearance from reality. It is the Congress, through staff work and committee hearings, which has been better able to identify the needs of biomedical research at ADAMHA and NIH than the staff at OMB. It will again be up to Congress to identify those needs and to identify the funds that will pay for these programs.

The Ad Hoc Group for Medical Research Funding, an organization whose membership has historically been concerned about NIH funding, is this year urging an increase in ADAMHA funding which would enable mental and addictive disorders research to "catch up." The budget that they recommend would restore ADAMHA "purchasing power for research and research training to the constant dollar level of 1974." In essence this group, and a coalition of citizen's organizations concerned about the future of research support for ADAMHA, have identified an alternative budget for this agency which is based upon professional judgments of present programs and critical need. The proposed budget recognizes the essential interconnectedness of individual research grants, research centers, research training of new investigators, research career development awards, support for equipment and support for intramural programs at all three institutes. The professional judgment budget calls for research support of $272 million at NIMH; $72 million at NIAAA; and $90.5 million at NIDA (Total: $434.5 million). These budgets are based upon a realistic estimate of what will be required to continue research supported by ADAMHA. The numbers are somewhere between the President's proposal ($348 million) which is inadequate, and the 1984 recommendations of the Institute of Medicine which suggested $300 million for NIMH and $100 million each for NIAAA and NIDA.

The President's recommendations would slash the number of new and competing grants at NIAAA and NIMH by 25% and by 12% at NIDA. NIDA has already imposed huge cuts in new and continuing grants in order to meet Congressionally mandated numbers of new grants in FY '86. NIDA has also been forced to cut back its Clinical Research Centers grants; NIMH would be unable to fund any new or competing research centers -- and six of the highly productive Centers would be abruptly terminated because of the shortfall in the President's budget proposal for this agency. Over the years, students of research policy and the history of science have highlighted the importance of mission-based research centers to the advancement of knowledge. This has been no less true in university settings than in technology-based industries. Research centers have become a critical part of ADAMHA research (as at NIH) -- but they have sometimes been forgotten in the "numbers game" around new and competing investigator initiated grants. The President's budget would arbitrarily dismantle those centers whose turn happened to emerge in the review cycle. This is not science policy based upon a critical review of excellence; it is more akin to Russian roulette.

Finally, your staff members know from their own visits to research programs around the country that clinical research grants are usually more expensive than laboratory based research. This means that fewer clinical research grants can be funded with a given amount of money -- and those agencies which support more clinical research will be obliged to make large cuts in individual grants in order to meet mandated numbers of new and competing awards. On all grants, there has been a tendency to delete essential items of equipment in order to reduce costs. The net effect on all research has been an aging of instrumentation -- and a special crisis of funding of clinical research programs.

In December, in this city, ACNP will be celebrating its 25th anniversary and a coalition of citizens' groups (the National Alliance for the Mentally Ill, the National Association for Mental Health, the National Depressive and Manic Depressive Association, and others) will be sponsoring a companion meeting for members of Congress, spouses, Congressional staff and the media. Your committee members and staff have understood the importance of research on alcoholism, drug abuse and other mental disorders. I hope that you will be able to attend the meetings and share in the pride of what you have helped to build. Congressional support for biomedical and behavioral research has been firmly grounded in the mixture of idealism and optimism that has produced dramatic returns for this country. Gramm/Rudman/Hollings calls for deficit reduction; it does not call specifically for dismantling the biomedical research programs of this country. There are ways to reduce the deficit while strengthening our biomedical and behavioral research programs. Your own support in the past has given some hope to the scientific community; to the mentally disabled and their families. We are all deeply grateful for your efforts.

THURSDAY, MAY 1, 1986.

IMMUNE SYSTEM DISORDERS

WITNESSES

JACQUELINE BELLANTI, CHAIR, NATIONAL COALITION ON IMMUNE SYSTEM DISORDERS
MARCIA BOYLE
JOHN BOYLE
SUSAN GOLICK
MAGGIE PETITO
DAVEY PETITO
LEN KOCH

Mr. NATCHER. Our next witness is Ms. Jacqueline Bellanti. You have been before our committee a number of times. Go right ahead.

Ms. BELLANTI. I am accompanied by a few people today. I volunteered to chair the National Coalition on Immune System Disorders, which is a group of 12 organizations that are concentrating on research in the immune system and help in disease and the people I have with me today represent individuals with disorders and diseases of the immune system, and I would like them to introduce themselves.

Mr. KOCH. I am Len Koch, an insulin-dependent diabetic for over 25 years, and I suffer with diabetic retinopathy.

Mr. DAVEY PETITO. I am Davey Petito. Sometimes I can't speak well.

Mr. NATCHER. You have done a fine job.

Mr. GOLICK. I am Susan Golick, and I am here to represent lupus patients, close to a million in this country.

Ms. MARCIA BOYLE. I am Marcia Boyle, and my son John is one of tens of thousands of children and adults with primary immunodeficiency diseases. He is an A student, in second grade, plays several sports, and he has not been hospitalized in over five years. Is in a protective bubble, the drugs and treatments developed by the National Institutes of Health, and children like Johnny all across the country hope you will support their future.

Mr. JOHN BOYLE. I am John Boyle. Thank you for what you have done for me. I hope you will help other children who are not as lucky as me.

Mr. NATCHER. Thank you, John.

Ms. BELLANTI. We have two young people with us today. In addition to the individuals we have before us, there are an estimated 65,000,000 more Americans with problems of the immune system, so we are here today to speak with one voice on behalf of research on the immune system, and the urgency to continue not to cut research, and to expand, not to decrease the funding for that research.

First, and most importantly, we would like to express our sincere appreciation to you, Mr. Chairman, and to Mr. O'Brien, and the other members of this committee for your outstanding support and strong commitment to research endeavors in the field of immunology.

It has been because of your continued efforts that the immunology initiative has flourished, and because of this, we are closer to learning more about the immune system and its important functions. Thank you for your encouragement in the past, but we ask you not to abandon us now.

I would like to draw your attention to the brochure attached to this testimony, as it contains the names of the Board of the National Coalition on Immune System Disorders:

The AIDS Action Council; the American Academy of Otolaryngology Head and Neck Surgery; the American Lung Association; the Arthritis Foundation; the Asthma and Allergy Foundation of America; the Immune Deficiency Foundation; the Joint Council of Allergy and Immunology; the Lupus Foundation of America; the National Foundation of Ileitis and Colitis; the National Multiple Sclerosis Society, and the Terri Gotthelf Lupus Research Institute.

Broadly speaking, our statement of purpose is our profound and continued interest in the immune system in health and disease, and the need for research on that system, as well as the translation of that research to the benefit of the American people.

With the increased knowledge of the immune system and the explosion of information on that system, there is heightened expectation of the application that research on the immune system may lead to.

Recent research efforts in basic and clinical immunology have put us on the threshold of discovering new insights in the mechanisms of this complex system which can lead not only to improved methods of diagnosis and treatment, but conceivably curing some of these disorders of the immune system.

Will all this research disappear? If this research diminishes, so does the hopes of millions of people who depend on this research to sustain them not only in their daily living but in research lies the hope for cures and improved treatment.

There are those who wish to tell this to the American people: "There are more important issues than research for your disease."

Consider the impact of the challenge facing researchers today. It is estimated that approximately one in four Americans has a disorder or disease of the immune system.

73,000,000 Americans have chronic respiratory problems.

40,000,000 Americans have asthma or allergic diseases.

38,000,000 Americans have arthritis and 250,000 are children.

500,000 Americans have systemic lupus erythematosus, a nine to one ratio of which are women.

11,000,000 Americans have diabetes.

250,000 Americans have multiple sclerosis.

19,000 Americans have AIDS and over 1,500,000 are infected with the virus.

250,000 Americans have an immune deficiency disorder.

20,000,000 Americans have hearing impairment.

2,000,000 Americans have ileitis and colitis.

The range of diseases is great: Allergies to arthritis to AIDS. The quality of life for those with immunologic disorders is equally diminished. There are many other serious diseases and disorders, including cancer, which are suspected to be related to immune system dysfunction.

The NCISD is appealing today with one voice to support the immunology initiative begun in 1981 by this committee and to fund it to the degree where research efforts may afford a breakthrough for the cure for many disorders of the immune system.

The statements that follow reflect the importance of research in the field of immunology and the impact that cutbacks have had and what the future holds:

American Academy of Otolaryngology Head and Neck Surgery:

More than 50,000 Americans will develop cancer of the head and neck this year. 15,000 of them will die. Immunological techniques and interventions are our most exciting avenues to earlier diagnosis and more effective treatment for these patients.

Autoimmune diseases often affect hearing and balance. A significant number of young people who see an otolaryngologist about recurrent dizziness are experiencing this vertigo as the first symptom of multiple sclerosis.

We know too little about the relationship of the immune system to normal hearing and balance. We are concerned, too, with better treatment of infections and allergy affecting the ear, nose and throat and with improving the outcome of any surgery involving the head and neck.

We are already taking advantage of new knowledge about the immune system. However, the continuing uncertainty over actual and future levels of Federal funding for health-related research is seriously compromising our ability to evaluate promising new strategies of care for our patients.

Efforts to restrain Federal spending cannot be allowed to strangle clinical application of what we have already learned about the immune system, Mr. Chairman.

Our patients need increased NIH support of immunological research, training and clinical research, not less. Actions taken in fiscal year 1986 and contemplated for fiscal year 1987 will have long-range consequences.

Fewer talented young men and women can be attracted into clinical research centers when they see their mentors losing grants and constantly scrambling to keep important projects going despite cuts in funding.

Even the most creative clinical investigators must now divert so much time to fund-raising that valuable studies simply go undone or are delayed indefinitely. Some experienced investigators have abandoned clinical research altogether.

If this continues, damage to the remarkably productive relationship between the Federal Government's National Institutes of Health and the biomedical research community will take years to repair and a whole generation of patients will endure needless death and disability.

American Lung Association:

The lungs remain the single most common target organ for infection in immunocompromised patients, which include patients undergoing cancer chemotherapy, recipients of an organ transplant, or those who are generally debilitated.

Such patients are subject to "opportunistic" infections by a wide variety of common microorganisms that rarely cause disease in immunologically normal persons.

More recently, these infections have been seen in patients with AIDS. Through better definition of various naturally occurring defenses against infection, such as Interferon, and with the use of recombinant DNA technology to supply these projects in large amounts, effective treatment and prevention could take a giant step forward.

National Multiple Sclerosis Society:

Multiple sclerosis is now thought to be a neurologic disease of immunological origin. Tremendous strides in understanding the immune system are being made by the NIH. Cutbacks in biomedical research would be cruel, shortsighted and in the long run, very costly by delaying cures for multiple sclerosis and other immune system disorders that costs billions in health care.

American Diabetes Association:

Research regarding the immune system is relevant to the disease diabetes mellitus. Diabetes mellitus is a chronic disorder characterized by abnormalities in the metabolism of carbohydrate, protein and fat.

It is thought that insulin-dependent diabetes is an autoimmune disease, in that the body unexpectedly begins to make antibodies against its own pancreas, thereby destroying the insulin secreting function of this organ.

The event that triggers the autoimmune reaction, as well as a thorough understanding of the autoimmune process itself are unknown. More research in this area would undoubtedly lead to ways to prevent and possibly cure diabetes.

Asthma and Allergy Foundation of America:

We are dedicated to serving the 40,000,000 Americans with asthma and allergic diseases by supporting scientific research to find the means to prevent and ultimately cure these disorders.

Research on the immune system and its functioning is vital to the cause and cure for asthma and allergic diseases. We are concerned that cutbacks will diminish the number of research centers devoted to research on asthma and allergic diseases and that the pool of investigators will be so diminished that cures through research will be impossible.

AIDS Action Council:

Recognizing that AIDS is one of the most serious threats to the body's immune system to appear in this century, the AIDS Action Council places top priority on securing funds to support immunological research and treatment.

Scientific advances in AIDS-related immunological research will significantly enhance the fight against all immune system disorders. Of particular importance are plans to develop drugs that block the antigenic assaults on the body's immune system as well as drugs that strengthen the immune system's ability to fight off infection.

Terri Gotthelf Lupus Research Institute:

Lupus is not a rare disease. One out of 700 women suffers from lupus, the majority in their twenties and thirties. Despite the prevalence and pervasiveness of this disease, we still do not know the factors causing it, nor how to prevent or cure it.

Through the Terri Gotthelf Lupus Research Institute and working with the governmental and private sectors, we hope to move forward against this deadly disease by improving the effectiveness of our research programs on immune diseases.

Joint Council of Allergy and Immunology:

The JCAI, comprised of the American Academy of Allergy and Immunology, the American College of Allergists, and the American Association for Clinical Immunology and Allergy, feels that progressive research on the immune system is critical in the eradication of asthma and allergic diseases, which are among the Nation's most common, costly and misunderstood health problems.

Cutbacks in research can only prove to be far more costly in the long run for the government in treatment for the millions of Americans afflicted with these disorders.

Arthritis Foundation:

This Foundation is the only national voluntary health agency working to find the answers for all forms of arthritis as well as supporting public and professional education programs.

In certain types of arthritis, the immune system malfunctions so that healthy body cells are attached by antibodies, thus research on the immune system is of great importance to people with arthritis, arthritis researchers and the Arthritis Foundation.

National Foundation for Ileitis and Colitis:

The NFIC is devoted to raising funds to discover the elusive cause and cure for Crohn's disease and ulcerative colitis. It is estimated that as many as 2,000,000 Americans have these disorders and they are primarily diseases of the young.

The body's immune system appears to play a significant role in both the susceptibility to and the course of the inflammatory bowel disease. The cure for ileitis and colitis lies within the mysteries of the immune system and further research is needed to find the answers and provide hope to the more than 2,000,000 Americans, of which there are 200,000 children under the age of 16 years.

The Immune Deficiency Foundation: The IDF was founded in 1981 to promote scientific research into the cause, prevention, treatment and cure of the primary immune deficiency diseases. The Foundation also supports clinical training and coordinates and disseminates information concerning research and treatment of these diseases.

Of great interest is the need to expand research in the developing immune system in infants and children because of the susceptibility of the developing infant to infection is related to the immature immune system and research is vital to determine both the cellular and humoral mechanisms of the defense system to answer why they are more vulnerable.

Lupus Foundation of America:

Systemic lupus erythematosus, an autoimmune disease of unknown cause, afflicts 500,000 people in the U.S., with 16,000 new victims each year. The LFA and its 95 chapters across the country seek to promote public, professional and patient awareness and education and encourage, monitor and directly sponsor research on the causes, treatment and cure of lupus.

Annually, the LFA awards several research fellowships and grants. However, this debilitating and sometimes fatal disease, which disproportionately strikes women and minorities, requires continued and strengthened public research support if the cause of and cure for lupus are to be soon found.

One of the things we are most concerned with the cutbacks is what is going to happen to the priorities that these Institutes have projected, particularly in terms of research and the immune system.

Since this committee has demonstrated its support by creating and nurturing the immunology initiative of 1981, we suggest report language to assure the following a critical mass of well-trained immunologists, and we need to provide adequate training for grant support and encourage immunology research so young people like John will be able to find out what their immune system is lacking in the beginning, and to encourage clinical trials.

And little Davey is treated at one of the centers developed by this program.

Methods to treat and encourage, and research in immunology is our best investment for the future. Without research there is no hope, and without hope, nearly one of out four people in the United States will be looking for things to encourage them.

Mr. Chairman, I wish to thank you very much for the opportunity to present this testimony to you today and we would be very happy to answer any questions you may have.

[The information follows:]

Congressional Initiatives

The NCISD is a member of the Ad Hoc Group for Medical Research and supports the recommendations of a budget of $6.1 billion for the NIH. This is a modest program growth of about $86 million or 1.4% over the current services budget. This increase provides funds sufficient to support research activities at levels provided by the FY 86 congressional appropriations with only a modest increase for a varietv of important programs to conduct basic and clinical research, train qualified promising investigators and translate that research and technology to the benefit of the public. This Committee has demonstrated its support by creating and nuturing the immunology initiative of 1981 and to further this research initiative, the NCISD requests report language to assure the following:

- a critical mass of well-trained immunologists to provide necessary skills and expertise; need to provide adequate training grant support;
- encourage immunology research on the maturation of the immune system during development, fetal and neonatal host defenses against infection and disease;
- growth in research career awards to develop vigorous research groups at medical schools specializing in immunologic diseases;
- encouragement of clinical trials to assure the continuation of scientific outreach and technology transfer for the benefit of the public;
- additional and separate funding for the cause, treatment and cure of AIDS--the major health crisis of this century;
- support of research centers to full funding to assure the clinical research efforts on the cause, prevention and treatment of asthma, immune deficiencies and autoimmune disease. Fully support the core outreach of centers for the education and technology transfer components;
- develop methods to treat colitis, ileitis and other intestinal disorders, many of whom have immunologic origin;
- needed upgrading and renovation of primate centers and outmoded and inefficient research laboratories--both intramurally and in medical school settings;
- support for intramural and R&D contracts to maintain all on-going efforts in respiratory, immunologic, rheumatologic and autoimmune diseases;

Research in immunology is our best investment in the future; to support it we need the scientists, clinicians and the funding to provide hope for the more than 65 million Americans with immunologic disorders. Thank you Mr.Chairman, Committee members for the opportunity to present before you today.

Mr. **Natcher**. Mr. O'Brien?

Mr. **O'Brien**. It is good to have you back. It is good to have you bring people before us to dramatize what you are trying to do, and what we are trying to implement.

Dr. Sabshin referred to it lightly, and I don't know whether Dr. Meyer did or not, but staff recalls to me an experience I had at NIH. I was out there because of a back problem, disc and vertebrae difficulties, and I have got this girdle on, and I really had quite a time out there.

I was amazed at how professional is their care. I went around to most of the Institutes to see how they were doing. I saw an awful lot of empty beds. It occurred to me that there are a lot of people not unlike Davey and John, who could be treated and corrected, and maybe we would turn corners with respect to old diseases, if we had an opportunity to take care of them.

The difficulty with adding patients was this business of not having enough "full-time equivalents." In short, full-time equivalents mean staff, and staff mean that the beds will be occupied by patients who need the treatment.

I want you to know that when you are before this committee, before Bill Natcher and George O'Brien, you are advising Joan of Arc to support the volunteer fire department.

We feel very strongly about what you are doing, and we are going to see what we can do in order to make certain that the NIAID will get the full-time equivalents they need.

Ms. **Bellanti**. Mr. Natcher, the good news is the empty beds. The bad news is the quality of life that people are trying to sustain without research in their endeavors, and so like Joan of Arc, we have to keep coming to you to remind you in spite of all of the cutbacks without this committee to keep guard on what is happening, we won't have anyone to carry our banner for us.

Mr. **O'Brien**. That suggests to me that there are people lined up to get into those beds, and we don't have the staff to care for them. If we lose the professional people—from the most proficient physician to the lowliest water boy—we are not doing our job.

Most private enterprise hospitals are way ahead of NIH. The empty bed is a condition that should not exist. We are going to try to correct that.

Mr. **Natcher**. Thank you very much.

Thursday, May 1, 1986.

NATIONAL INSTITUTE OF DENTAL RESEARCH

WITNESS

DR. ERROL L. REESE, DEAN, SCHOOL OF DENTISTRY, UNIVERSITY OF MARYLAND, AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Mr. **Natcher**. Our next witness is Dr. Errol Reese. Come around, Dr. Reese. We are glad to have you before the committee, and we will be pleased to hear from you.

Dr. **Reese**. Mr. Chairman and members of the committee, my name is Errol L. Reese. I am Dean of the Baltimore College of

Dental Surgery, Dental School, University of Maryland, and Professor of Prosthodontics.

I am appearing before you today on behalf of the American Association for Dental Research. The members of the Association appreciate having this opportunity to present testimony regarding the 1987 budget for the National Institute of Dental Research.

I am also proud to be a member and honored to be able to present this for the some 4,000 very dedicated American Association of Dental Research Scientists.

The membership of the AADR consists of over 4,000 scientists from a variety of basic science and clinical disciplines located in universities, research institutes, hospitals, and industrial laboratories around the country.

Our principal objective is to study the causes of the major diseases affecting the teeth and oral-facial region, and to seek ways of controlling and/or preventing these diseases.

The field of dental research involves basic and applied research related to the causes, prevention and methods of diagnosis and treatment of oral diseases and conditions.

The areas of research pursued by dental scientists include the following:

Caries, tooth decay.
Periodontal diseases, gum diseases.
Oral cancer and other soft tissue lesions.
Congenital craniofacial anomalies.
Temporomandibular disorders.
Taste and smell disorders.
Pain.
AIDS.
Herpes.
Salivary glands.
Biomaterials.

The research on these disorders requires a wide range of scientific disciplines of some from early childhood until death. In fact, oral and dental diseases constitute, in the aggregate, the most prevalent health problem in the Nation.

The monetary cost to society as a result of oral disease is high. In 1984, according to the Department of Commerce, Americans spent $19,800,000,000 for dental services. To this figure must be added the time lost from work, estimated to be 32,000,000 days, and reduced productivity caused by pain and discomfort.

With the aging of our population, we are beginning to see more of our senior citizens experiencing caries on the root surfaces of their teeth. As people age, the gums around the teeth recede, exposing the root surfaces, thus permitting bacteria to attack those surfaces.

When this occurs, the roots are destroyed much more rapidly than are tooth crowns, leading to sudden and serious problems in tooth retention.

In addition to the specific problems of the elderly, there are many other areas requiring continued research attention; for example, the number of babies born with facial deformities, and the high incidence of oral sores caused by the herpes simplex virus.

As you can see, oral diseases affect every age group in our society.

Dental science has yielded new discoveries which point to important new preventive measures for oral diseases.

For example, periodontal diseases: Studies of unique forms of periodontal disease are contributing to better understanding of the pathogenesis of and immune responses to these diseases.

Defective polymorphonuclear white blood cells have been shown to be an important factor in juvenile periodontitis, a severe form of periodontal disease that runs in families.

The PMN cells fail to migrate rapidly to the sites of infection. This failure has now been attributed to the absence of a single cell surface protein. Lack of this protein in a child in a family with JP might also indicate that the child is at risk for the disease.

A newly-defined syndrome which affects young children, pre-pubertal periodontitis, also appears to involve PMN defects; in this case, complete inability of the cells to migrate to the site of infection.

Other studies have explored the reasons for the fact that diabetic patients are highly susceptible to periodontal diseases. One study found reduced cellular uptake of ascorbic acid in the cells of diabetic patients, compared to similar uptake in cells of normal patients.

Three approaches to controlling herpes simplex virus infections are under study. The first approach is prevention through the use of a genetically engineered vaccine composed of a herpes simplex virus cell surface antigen gene and the vaccinia virus.

In experiments conducted a year ago, this vaccine proved effective in protecting mice against both herpes simplex virus type 1, oral, and herpes simplex virus type 2, genital, infections.

When administered prophylactically on a daily basis, the drug acyclovir has been shown to reduce the frequency of reactivation of genital herpes.

A third approach is aimed at identifying the processes involved in triggering reactivation. These studies have implicated ultraviolet light as a trigger and are allowing investigators to study the early skin changes that precede overt herpes lesions.

Work continues on understanding the multiple mechanisms by which fluoride protects developing enamel and assists in remineralizing early caries lesions. Efforts to reduce the prevalence of caries beyond levels already achieved are emphasizing studies of oral ecology and immunology.

Scientists are testing the feasibility of blocking mother-to-infant transmission of Streptococcus mutans, considered to be the principal cause of tooth decay, by using non-virulent strains to co-opt colonization sites in erupting teeth.

Ongoing immunological studies are focusing on improving understanding of the secretory immunity and studying a variety of candidates for an anticaries vaccine.

Also, public awareness of caries-preventive measures appears to be growing, as reflected in the increased demand for and provision of dental sealants by the profession for the prevention of decay on occlusal surfaces.

In a five-year clinical study, researchers are testing new adhesive materials and methods of application that will permit bonding of restorative materials to both dentin and enamel.

Also under investigation is the feasibility of using sealed composite restorations to arrest caries lesions without cavity preparation and without removal of the lesion material.

Such treatment is unlikely to require anesthetic injection and also conserves tooth structure. Further, the sealed composite restorations are being compared to standard amalgam restorations.

Members of the committee: If research momentum is to be maintained, then continued attention must be given to ensuring the future availability of a variety of investigators to staff dental schools and dental research institutes.

In the past two appropriations bills, this committee has provided support for the Dentist-Scientist Award, and we in the community deeply appreciate your support. However, in order to continue the work you have begun, we respectfully request that an additional $1,500,000 be provided for this program in 1987.

There are three components to the Dentist-Scientist Award program. Namely:

Advanced basic science development: To develop requisite knowledge and research skills in needed basic science areas.

Advanced clinical science development: To ensure that the candidate has the requisite advanced clinical knowledge and skills.

Research experience development: To provide an intensive research experience that will facilitate the individual's transition from trainee to active investigator.

Mr. Chairman, an important tactic in the strategy for solving oral health problems has been the establishment of centers to focus research efforts on specific disorders, such as periodontal diseases and tooth decay.

This type of multidisciplinary and concentrated approach will accelerate development of needed information, as well as coordinate the application of all dental research findings toward the prevention and cure of dental diseases.

At present, centers for pain and oral biology are under consideration. However, additional centers are needed for geriatrics, restorative dentistry, temporomandibular joint problems, and core grant administration for the individual grantee.

In short, these centers fill an important gap in the program of dental research, and thus, the committee is urged to provide funding for an additional six centers.

The investment of the public's funds in the research programs of the National Institute of Dental Research is, and has been, paying dividends. One has only to look at the reduction in the prevalence of dental caries and the expanding knowledge base about the causes of periodontal diseases to see the rate of return on the investment made to date.

We believe that through your continued support, the dental research community can and will make significant progress toward solving the multitude of oral diseases confronting our society.

Unfortunately, Mr. Chairman, the President's 1987 budget for the National Institute of Dental Research is not adequate to maintain the current program level, nor will it permit the Institute to expand significant and promising areas of research.

While we are fully aware of the difficult budgetary pressures facing the Congress, we believe that adequate funding for the Nation's biomedical research enterprise can be achieved through a reordering of the priorities in the President's budget.

It is with this in mind that we respectfully request a 1987 funding level for the National Institute of Dental Research of $115,000,000. This level will allow for a balanced research program in dental science.

Mr. Chairman, this concludes my testimony as it relates to the National Institute of Dental Research. At this time, I would like to take the opportunity to address three additional program areas which provide important support for the research conducted and supported by NIDR.

Specifically, I would like to call your attention to the Biomedical Research Support Grant Program, BRSG, which is being proposed for elimination in the President's budget. This program is designed both to meet emerging opportunities in research on and pursuit of new ideas, and to develop young scientific talent.

The BRSG has become an important part of the dental research effort in this country. We believe the loss of this program will weaken institutional research in the health sciences. Therefore, we urge the committee to restore this program to at least its 1986 level.

A second area of concern is that we must continue obtaining adequate information on disease status in order to direct research appropriately. For this, the support of the National Center for Health Statistics is of vital importance, and it should be funded accordingly.

Third and finally, to ensure the most effective implementation of dental research findings, the National Center for Health Services Research and Health Care Technology Assessment provides a vital role, and we urge adequate funding for this Center as well.

Thank you for this opportunity to testify, and I will be happy to answer any questions. Thank you for caring.

Mr. NATCHER. Doctor, you have made an excellent statement. We appreciate your appearance before the committee. Thank you very much.

THURSDAY, MAY 1, 1986.

SPECIAL PROGRAMS FOR THE DISADVANTAGED

WITNESSES

HON. CARL C. PERKINS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF KENTUCKY

ARNOLD MITCHEM, EXECUTIVE DIRECTOR, NATIONAL COUNCIL FOR EDUCATIONAL OPPORTUNITIES

WALTER BLEVINS, MEMBER, KENTUCKY LEGISLATURE

Mr. NATCHER. Our next witnesses are Dr. Arnold Mitchem, Dr. Walter Blevins, and we also have with these two gentlemen our kins played a vital role in that in the years he was there, and Governor Collins of Kentucky brought this issue before us again in a special session, and we put a record amount of funds into education.

Just this session, which concluded April 15, we put a record amount of money into higher education, more money into student loans because of the proposed Federal cutbacks, but I am here to ask you to place more money in those programs.

Still, we can't meet the needs in Kentucky of the people that need the money to go on to school and to have those opportunities. We are caught in the middle in that coal is depressed, and tobacco is depressed.

People like myself who want to be productive citizens will be afforded that same opportunity. I can't say enough for Upward Bound and TRIO.

It gives the people of my region an opportunity, and that is what America stands for, is a land of opportunity, and with these cutbacks, and with the economy in Kentucky, those opportunities are being diminished daily.

I hope that my coming here today will make you more aware of the needs in eastern Kentucky. I am sure my former colleague, Congressman Perkins, has carried the banner for us, but oftentimes, it is good to hear from someone else.

Again, we rank 46th in per capita income in Kentucky, and we rank very low in the number of high school graduates. 50 percent of people over the age of 25 do not have a high school diploma or equivalency.

There is a lost generation of people out there, and if we don't prop up these programs we will have another lost generation of citizens, and a mind is a terrible thing to waste, and these programs are an attempt to bring those minds, to give them a opportunity to get a higher education and to be productive citizens.

In Kentucky, I represent Morehead State University, the only regional university in eastern Kentucky, and 80 percent of the students receive some type of financial assistance, Federal or State dollars.

With cutbacks in Pell Grants, TRIO, special services, these people will not have an opportunity to excel and to become productive citizens. That is why I am here today to address issue and get that point across to the Congress of the United States, that in a time when we are in large deficits, I think it is penny-wise and pound-foolish to be cutting back on educational endeavors.

Those types of programs pay dividends. In the testimony prior to me about immune and dental disease, I am also a dentist, those types of programs will pay dividends for us. I hope that we can come together and find some solutions, that we can keep putting more money into those areas, because again they will help us solve the problems of this world.

The rest of this information is in my written testimony. I would just like to address one other issue, and that is there was around $350,000 that could be taken out of special services.

Right now, they are talking about, and I may let Mr. Mitchem speak to that, these grants, they have people to review them, have friend and colleague in the House of Representatives, Chris Perkins, who represents the Seventh District of Kentucky, and he is doing it well.

Mr. PERKINS. Mr. Chairman, I just found out my dear friend and colleague, Walter Blevins, came to town today. Walter and I were elected to the State Legislature in Kentucky at the same time, and began our service at the same time, and during that time period, I became intimately acquainted with Walter Blevins. He is one of the most dedicated, hard-working individuals we have in the Kentucky General Assembly, and he cares about people and takes his job seriously.

Whenever he says something that has to do with people, I pay a great deal of attention to it, because I know it comes from the heart, and a good mind.

I have not worked with Dr. Mitchem quite as much as I have with Walter, but I know with George and the distinguished ears that you have on you, I would like you to listen to those CLE courses, we are going to listen to some good testimony here today.

I want to take this opportunity to bring him over and try to say some words about him, so you know you are listening to a fine fellow today.

Mr. NATCHER. Gentlemen, we are delighted to have both of you.

Mr. MITCHEM. Mr. Chairman, it is nice to be back with you, and I have the distinct privilege of introducing Dr. Walter Blevins, a former TRIO student. He represents the 71st District of Kentucky.

Dr. BLEVINS. Mr. Chairman, after such a fine introduction by both these fine gentlemen, I don't know what else to say, except thank you.

I would not read from the prepared remarks, but try to address some of the issues that are bothering me, and are pressing issues of the region that I serve.

Again, I appreciate the opportunity to come before this august committee. I know that it is like preaching to the choir, I guess, as the lady before me said.

Perhaps it is, because I know Mr. Natcher has been active in these types of programs for many, many years. Mr. Conte and Mr. Stokes have passed the resolution to make a TRIO National Day, February 28.

I commend you for that, for doing that.

I am an Upward Bound student, a product of these TRIO programs. As a young man from eastern Kentucky, I wasn't afforded the opportunities others may have been afforded. We had poor schools, a lack of biology labs, chemistry labs, and to be—or to want to become a dentist and not have the facilities, it puts a damper on your educational process, but now I am speaking as a representative of the people of the 71st District.

We have abject poverty still in eastern Kentucky. There are people that have very little hope of every getting out of that unless they are afforded some of the same opportunities I was afforded.

At this time in the Gramm-Rudman-Hollings Act, in the State of Kentucky, we are trying to pick up those pieces, and trying to address those issues.

We have raised taxes in a special session, to put more money into education, raise the educational level, and Congressman Per-fairness, people throughout the United States, they are looking now at maybe doing away with this process.

What it will do will cause some unfairness in the process, and some people will not feel like in certain parts of areas that they are being treated fairly, because they are not having people throughout the United States.

It is only about half of 1 percent of the money, but it could be used wisely to assure that fairness is being used in the process.

That concludes my testimony, Mr. Chairman.

[The statement of Dr. Blevins follows:]

NCEOA

National Council of Educational Opportunity Associations

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Association for Equality and Excellence in Education, Inc

Association of Special Programs in Region Eight

Caribbean Association of TRIO Programs

Mid America Association of Educational Opportunity Program Personnel

Mideastern Association of Educational Opportunity Program Personnel

New England Association of Educational Opportunity Program Personnel

Northwest Association of Special Programs

Southeastern Association of Educational Opportunity Program Personnel

Southwest Association of Student Assistance Programs

Western Association of Educational Opportunity Personnel

TESTIMONY OF WALTER BLEVINS, D.M.D

INTRODUCED BY

ARNOLD L. MITCHEM, EXECUTIVE DIRECTOR

NATIONAL COUNCIL OF EDUCATIONAL OPPORTUNITY ASSOCIATIONS

REPRESENTATIVE FROM THE 71ST LEGISLATIVE DISTRICT OF KENTUCKY

BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

REGARDING

SPECIAL PROGRAMS FOR STUDENTS FROM DISADVANTAGED
BACKGROUNDS (TRIO)

May 1, 1986

THE NCEOA RECOMMENDS A FUNDING LEVEL OF $187
MILLION FOR TRIO FOR FISCAL YEAR 1987

Fifth Annual Conference
"Trio: Committed to the Promise of Equal Educational Opportunity"
September 21-24, 1986 • Hyatt Regency-Capitol Hill • Washington, DC

Mr. Chairman, Members of the Subcommittee, I very much appreciate the opportunity to testify before you today. I particularly appreciate the opportunity to voice my support for the continuation and expansion of federal programs which provide postsecondary educationl opportunities in eastern Kentucky. I have benefitted from the federal student assistance programs, TRIO and Upward Bound in particular, and I know the important role Congressman Natcher has played in developing and protecting these initiatives.

My name is Walter Blevins and I represent the 71st legislative district -- Morgan, Rowan and parts of Lawrence and Lewis counties -- in the Kentucky legislature. I am also a practicing dentist in Morehead, Kentucky.

In 1966, while a student at Morgan County High School, I was recruited into the Upward Bound program at Morehead State University. Through the program I received exposure to new opportunities and options of which I would have been unaware. The summer session, for example, gave me a chance to work in a biology laboratory and strengthened my mathematics and science preparation. I was able to attend plays and other cultural events which I had not seen before. In the process, I developed the self-confidence to know that I could do well in college. I was the first in my family of seven to graduate from college.

The services that I benefitted from from 1966 to 1968 remain important in my district today. You are aware, I am sure, that many residents of Kentucky, and eastern Kentucky particularly, are poor. Kentucky is ranked 46th in the nation in terms of per capita income. As an example, in the high school which I attended, one-half of the students now enrolled are from low-income families.

The educational needs of my constituents are substantial. Forty-eight percent (48%) of the citizens of Kentucky who are over 25 have not graduated from high school. In all of the high schools in my district, over 40% of the students who begin the ninth grade do not complete the twelfth. The rate of college completion in the state is only 60% of the national average. Yet Kentucky has only limited state resources to bring to these problems. Its per pupil expenditures rank 43rd in the country.

The TRIO programs supplement local resources and provide deserving young people and adults a chance to lead productive lives in jobs of their choice. In the 7th congressional district, for example, two Talent Search programs -- at Morehead State University and at Pikeville College -- provide information about college, career planning and student financial aid to 1500 students. Without Talent Search many of these students might not know about federal grant and loan programs, and might not consider going to college. Despite this great need, two of the counties which I represented in the past are not served by Talent Search, because of insufficient funds. One of these is Menifee County which ranks as the poorest county in Kentucky.

Upward Bound programs, such as the one I attended at Morehead, provide intensive support to disadvantaged young people while they are in high school. Supports include counseling, tutoring and special summer classes. In my work with the Jaycee's and Optimists' youth projects, I have come in contact with many young people who could benefit from Upward Bound, but only 200 are served each year by the two projects in the seventh district.

When Appalachian students do enroll in college, many require special support if they are not to become discouraged and drop out. That is why I am pleased that Morehead, Pikeville and Ashland Community College each sponsors a Special Services project. Young people leaving isolated rural communities and the support of families to attend college, benefit from the special counseling Special Services provides. Similarly, if disadvantaged students want to go into careers in the sciences, mathematics, or computers, many times they require tutoring or developmental classes to give them the background that their high schools -- because of limitations in faculty or resources -- were unable to supply.

Reversing the Decline In Equal Educational Opportunity

Members of the Subcommittee, I am well aware that the Subcommittee has already demonstrated its strong support for the TRIO programs. This year, Mr. Conte and Mr. Stokes were principal cosponsors of the House Concurrent Resolution 278 designating February 28 National TRIO Day. Last year, TRIO was one of a very limited number of programs designated for increases by the Subcommittee.

Nevertheless, despite your support over the past six years, the TRIO programs have suffered a very serious and marked decline. Over one hundred thousand students have been eliminated from these programs. Over this period, the effective dollars available to TRIO students has dropped 36%. This year alone, 23 of the presently funded Upward Bound programs will be eliminated.

The National Council of Educational Opportunity Associations is requesting $187 million for the TRIO programs in FY 1987. This will restore the 4.3% cut by Gramm-Rudman, adjust for inflation and add 1% for restoration. Even so, 16,000 fewer students will receive services in FY 1987 than received services in FY 1985. The chart on the following page details enrollments in the TRIO programs since 1980 and the implications of an appropriations level of $187 million for TRIO in FY 1987.

Mr. Natcher, Members of the Subcommittee, there is one additional matter which I would like to bring to your attention before I close. In the past, TRIO programs have been funded on the basis of written proposals and reviewed by teams of qualified outside readers who have been convened in Washington. These panels have been given a thorough orientation and generally received adequate supervision by Department of Education personnel. Panel members have received limited compensation for this work and their travel costs to Washington have been covered. In short, the process has had a high degree of integrity and viewed by most observers as fair.

In an effort to reduce costs, the Department now proposes to have proposals read in varying locations in the country by Departmental staff and other volunteers, many of whom may lack the the relevant experience and knowledge of the programs to make ininformed judgments about the merit of these applications for fiscal 1987 funding. Moreover, the NCEOA is convinced that such a process would undermine public faith in the impartiality and effectiveness of the review process. Such a situation would most likely cause a public uproar and generate widespread congressional concern next spring. For these reasons, we ask that you indicate your intent that funds from the TRIO appropriation be utilized to fund travel and compensation of outside reviewers to conduct all proposal review process similar to that conducted in FY 1985.

We estimate that the cost for proceeding in this manner would be no more than $350,000, or stated differently, about a half of one percent of the fiscal 1986 allocation for the 663 currently funded Special Services Programs for Disadvantaged Students ($70 million). It is the SSDS applications that will be reviewed for multi-year funding next year.

I appreciate the opportunity to testify before you today and would be pleased to answer any questions you might have.

FY 1980

	Dollars	Students	Projects
EOC's	7.7 million	117,000	32
Special Services	60.0 million	172,071	595
Talent Search	15.3 million	202,033	158
Upward Bound	62.5 million	37,210	437
Training	2.0 million	–	–
Total	147.5 million	528,414	1,222

FY 1985

EOC's	9.3 million	102,800	37
Special Services	70.3 million	141,580	663
Talent Search	20.3 million	185,560	175
Upward Bound	74.0 million	33,130	420
Training	1.0 million	–	–
Total	174.9 million	463,070	1,295

FY 1986 After March 1, Gramm-Rudman Cut

EOC's	8.9 million	94,260	37
Special Services	67.3 million	129,830	663
Talent Search	19.4 million	170,160	175
Upward Bound	72.2 million	31,120	397
Training	.9 million	–	–
Total	168.7 million	425,370	1,272

FY 1987 NCEOA Recommendations

EOC's	9.7 million	97,980	37
Special Services	76.1 million	139,890	663
Talent Search	21.2 million	176,670	175
Upward Bound	79.0 million	32,430	397
Training	1.0 million	–	–
Total	187.0 million	446,970	1,272

Mr. NATCHER. Dr. Blevins, you have made an excellent statement. We appreciate your appearance before the committee.

Dr. Mitchem, it is always a pleasure to have you appear. You are from the right part of the world.

Dr. BLEVINS. I agree.

Mr. NATCHER. I agree, and Chris Perkins, you come back to see us any time.

THURSDAY, MAY 1, 1986.

ADAMHA

NATIONAL ALLIANCE FOR THE MENTALLY ILL

WITNESSES

NANCY DOMENICI
NORMA LAGOMARSINO
JANE DENTON
CORRINE CONTE

Mr. NATCHER. Our next group of witnesses are Mrs. Domenici from New Mexico, Mrs. Lagomarsino from California, Mrs. Silvio Conte from Massachusetts, and Mrs. Denton from Alabama.

Come up and have a seat with us at this time. Mr. Conte, as you and I well know, Mrs. Domenici is the wife of the Chairman of the Budget Committee from the United States Senate.

Mrs. Lagomarsino is from California, and the wife of Robert Lagomarsino whose office is next to mine and one of the nicest men in the hall in that section of the Rayburn Building.

Mrs. Conte, it is a pleasure to have you back before the committee, and let me say this to you. You know, we all work hard on this subcommittee, we are all friends. When we mark our bill up, we sit at the table where you are sitting.

Silvio Conte and I took our bill over to the Floor and passed it in one hour and fifty three minutes. This bill used to be on the floor over four, five, six days, and I want you to know, Mrs. Conte, one of the nicest things that has happened to me since I have been a Member of Congress is the opportunity that I have had to serve with your husband.

He is not only the ranking minority member on this committee, but the ranking minority member on the full committee, and he is my friend.

Mrs. Denton, your husband is one of the good Senators in the United States Senate, and it is a pleasure to have you before the committee.

Ladies, we will be pleased to hear from you.

Mrs. DOMENICI. Mr. Chairman, thank you so much.

Actually, my name is Nancy Domenici, and since we have been introduced so much better by you than I could do, I think I will go ahead and testify.

Six spouses last year signed a letter asking for more appropriations for the NIH budget, and four of us are represented at this table, and if you might, I would like to include that letter with the written testimony.

Norma and I are members of an organization, sort of the new kids on the block, in the area of advocates for the citizens that have mental illness.

It is the six-year-old National Alliance for the Mentally Ill, also known as NAMI.

It is mainly comprised of friends and family of persons with chronic disabling mental conditions, such as schizophrenia and manic and major depressive disorders. But this particular child is growing fast; over 60,000 family members and 600 affiliates across the country.

At first, people join for emotional support, learning to cope with serious mental illness, but now members are advocates for services, policy change, and for rapid expansion, too, of much needed research.

We are grateful for this opportunity today and eager to offer our views on the budget and programs of the National Institute of Mental Health.

Research: The single most important government program to give the highest hope to mentally ill persons and their families is research, research into the causes and treatments of serious mental illness.

The Federal Government funds over 85 percent of research in the area of mental illness, and until the time private sources develop, the Federal Government is our main support.

We want to thank you and Congress for the dollar increases given the NIMH budget in the past few years. But these figures should not be frozen or cut.

Funding has lagged far behind in this research area; it has been so short-changed: $14 per person with schizophrenia versus $161 per person with multiple sclerosis or muscular dystrophy, $130 per person with heart disease; $27,000,000 spent last year on schizophrenia research versus $46,000,000 for teeth and gum diseases.

And if trend lines were weighed with inflation rates, results would show funding cuts. Congress needs to provide more money. Research opportunities exist now that did not several years ago, and it is cost-effective to exploit these areas now.

New research scientists must be attracted and kept. Knowing that five to 10 years of adequate funding was available would serve as a real incentive to attract scientists. Otherwise, they may go elsewhere.

Conversely, since many of these disorders occur in childhood, adolescence and young adulthood, years of providing special services and treatment, as well as food and housing are necessary.

Proper setting and specific support does allow many persons with mental illness to function better, but we are talking about billions, $52,000,000,000 lost in direct and indirect costs in services and lost productivity last year, and still there are many homeless and mentally ill citizens in jail. All of this compared to only millions for research.

By way of example, Mrs. Lagomarsino is here today with her experience.

Mr. NATCHER. We will be pleased to hear from you.

Mrs. LAGOMARSINO. I have a son who is diagnosed chronically schizophrenic, and I testified before a Senate Committee in 1985, and the reason I was able to do that, emotionally, I thought we were home free, but six weeks ago, we found out we were not.

We spent $7,000 in two weeks. We are happy again, because he has been able to go forward once again, so I guess we are part of that $52,000,000,000 that is spent.

What I wanted to stress was, it is not just the private monies, but it is the State institutions, and all of the homeless, and my son would be homeless if we didn't do this, and he could contribute to that person out there that looks like a bum or be part of the jail system.

With research, it is the only way we can move forward, because I thought we were home free, but we were not.

Mr. NATCHER. Your husband is not only my next-door neighbor, but he is one of the good Members of the Congress. He works hard, and he is my friend.

Mrs. LAGOMARSINO. He is my husband, and I agree with you.

Mr. NATCHER. He is all right.

Mrs. Domenici?

Mrs. DOMENICI. I will finish up real quick to say I am very acutely aware of the financial situation of our Federal budget.

In fact, I live with it, or I have with him, every day. But we ask you to look to a priority funding. Congress does and can respond to crisis needs and areas woefully underfunded.

AIDS is such an example. In two years, that program has grown to almost as much as the entire research budget. We applaud you for adopting priorities.

As a member of the National Advisory Mental Health Council, I want to stress today how sincerely we hope to see the continual focus, already begun at NIMH, toward a heavy emphasis on research into the most severe mental disorders.

But to enable them to follow this direction, we urge you, Congress, to find the funds, and appropriate more money. We plead with you to declare war on mental illness. With nearly 3,000,000 Americans struck down by these diseases, it is time for the Federal Government to move.

Mr. NATCHER. We are delighted to have you before the committee. You made an excellent statement.

The President has signed our bill each of the last three years. They told us from time to time the President would veto our bill. President Reagan signed our bill last year, and he signed it the year before, and the year before that.

We are going to bring out a good bill this time, and you tell your husbands. It is going to be one that you and I are going to like, and I hope over on the Senate side, that they will like it as well as we do on this side.

My friends George O'Brien, Silvio Conte and Lou Stokes, will tell you, we are going to bring out a good bill.

Mr. CONTE. Thank you, Mr. Chairman, for those kind remarks. The feeling is mutual. I have been here 28 years, and worked with a lot of Chairmen, and never worked with a better Chairman than Bill Natcher of Kentucky. We work as a team, and it is a bipartisan team.

We have had greater luck with this bill than any pair in the 28 years I have been on this Committee. We've gotten it signed more times than anyone else.

I want to complement the four wives for an outstanding job. Last year, when we went to conference, the Senate figure was below our mark in the area of mental health, and it was late and we had a real budgetary crunch. The Senate conferees wanted something else. We wanted the mental health research money and the thing that broke it was you four wives. I said to Lowell Weicker, if we don't put this in I can't go home tonight. That broke it. You really did the nation a good service last year, and I am sure you will continue your good service this year.

Mr. NATCHER. We understand the most serious problem we have in this country is our national debt, our deficit. We live with it every day. When I was first elected a member of this committee, we had $17,000,000 in the National Institutes of Health.

Last year, we had $5,500,000,000, and you ladies know, that is the way it should be. There is where we should spend our money, for the health of our people, and for education.

We are right proud of the fact that we succeeded in having the President sign this bill the last 3 years and we will bring out a good bill this time, and one that you ladies are going to help us with.

Thank you very much.

Mrs. DOMENICI. Thank you very much.

[The statements follow:]

FY '87 COALITION APPROPRIATIONS RECOMMENDATIONS FOR ADAMHA

Alcohol and Drug Problems Association of North America
American Academy of Child Psychiatry
American Association of Chairmen of Departments of Psychiatry
American Association of Directors of Psychiatric Residency Training
American Association for Counseling & Development
American Mental Health Counselors Association
American Nurses Association
American Occupational Therapy Association
American Orthopsychiatric Association
American Psychiatric Association
American Psychological Association
American Society for Adolescent Psychiatry
Americans for Substance Abuse Prevention
Association for the Advancement of Psychology
Association for Specialists in Group Work
Association of Psychiatric Outpatient Centers of the Americas
CareInstitute
Child Welfare League
Corporation for the Advancement of Psychiatry
Council of Graduate Departments of Psychology
International Association of Psychosocial Rehabilitative Services
Mental Health Law Project
National Alliance for the Mentally Ill
National Association of Private Psychiatric Hospitals
National Association of State Alcohol and Drug Abuse Directors
National Association of State Mental Health Program Directors
National Committee Against Mental Illness
National Council of Community Mental Health Centers
National Council on Alcoholism
National Mental Health Association
Therapeutic Communities of America

OVERVIEW

This document reflects the views of a coalition of organizations deeply concerned with the inadequacy of the President's proposed fiscal 1987 budget on people with mental disorders, alcoholism, alcohol or drug abuse problems, and with the impact of the President's proposed rescissions of fiscal 1986 spending. The coalition believes that funding for programs under the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) is now far too low, and has for some time been critically short of the need. This view is supported by the Institute of Medicine, in its report "Research on Mental Illness and Addictive Disorders: Progress and Prospects":

> "Mental disorders and addictive states, especially when severe or chronic, cause personal, economic, and social upheaval both for afflicted individuals and for those close to them. In the United States alone, conservative estimates suggest that mental disorders and addictions directly afflict 30 to 45 million people and cost $20 billion annually in direct health-care expenditures. They contribute especially to morbidity, using such measures as utilization of long-term care and Social Security Disability, and the indirect costs to society, including lost productivity, social services, and crime control. Overall, yearly direct and indirect expenses total an estimated $185 billion. Costs are especially high for the severe mental problems of childhood, which can produce lifelong debilitation. These data suggest that economic consequences of the disorders under the ADAMHA purview are comparable to those for heart disease and cancer."

Our coalition has analyzed the President's budget and is united in its opposition to these proposals. The President's budget focuses on large reductions in many domestic spending programs, including those of importance to mentally disabled people and those addicted to alcohol and drugs. Some of the most devastating proposals for the ADAMHA budget are the termination of demonstration programs, clinical training initiatives, state planning activities and the elimination of the new Protection and Advocacy program. In addition, the President proposes reductions in research and research training, at a time in our history when significant expansion in these areas is essential to enable us to capitalize on new knowledge about the brain and behavior.

While acknowledging the need to address budget deficits, our coalition does not believe human service programs, including those of ADAMHA, should bear the heavy burden of further cuts. These programs have been pared to the bone already, and Congress must look at alternative means to control the federal deficit.

The recommendations on the following pages would enable the federal government to maintain a leadership in support of ADM programs . . . Research, Services and Training.

We urge the Congress to seriously consider our recommendations as the FY 1987 appropriations process moves forward.

SUMMARY OF RECOMMENDATIONS

ADAMHA

(in $ millions)

	FY '86* Congressional Appropriation	FY '87 Current Services	FY '87 President's Budget	FY '87 Our Proposal
Research				
(NIMH)	214.0	237.0	199.0	272.0
(NIDA)	74.0	82.6	73.0	90.5
(NIAAA)	57.0	63.7	56.6	72.0
Research Training	21.0	22.7	18.5	31.3
Clinical Training				
(NIMH)	19.0	20.0	0	26.0
(NIDA)/(NIAAA)	1.0	1.0	0	2.0
Block Grant	490.0	525.0	490.0	576.0
State Planning	0	0	0	5.0
Community Support	12.5	11.0	0	20.0
Protection/ Advocacy	10.0	10.5	0	10.5
Direct Operations	62.5	63.0	58.5	65.6

* prior to Gramm-Rudman sequestration

NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) RESEARCH

(in millions of dollars)

FY '86	Current Services FY '87	President's FY '87	Our Proposal FY '87
$214.0*	$237.0	$199.0	$272.0

(* 204.7 after GRH)

The National Institute of Mental Health (NIMH) is this country's major funding source for research related to mental health. The President's Commission on Mental Health found that 90% of funding for mental health research emanates from the public sector. The 1984 Institute of Medicine report, "Research on Mental Illness and Addictive Disorders: Progress and Prospects," further documents the dependence of mental health research on NIMH funding and dramatically demonstrates how support for research on mental disorders has never achieved a reasonable level, especially when compared with support for comparably costly physical disorders. The historically inadequate levels of funding apply to support of the research infrastructure (i.e., such investigator-initiated programs as research centers, research scientist and career development awards) as well as traditional project grants and other research activities.

Scientific opportunities over the past few years have been particularly evident in the neurosciences, including behavioral research on understanding attention and memory, basic biochemical processes, the interactions between physiological processes and behavior underlying mental disorders and the effects of stress on the family unit. However, the President's budget seriously cuts back on even the current level of NIMH support nationally, sending a negative signal to research scientists as well as to individuals with mental disorders and their families, at the very time when substantial progress is being made.

Areas of research in which there are substantial opportunities and extensive needs include: application of newly available techniques in neuroscience and molecular biology to the study of schizophrenia and other psychotic disorders; the role of the brain and behavior in relation to Alzheimer's disease and other mental disorders; the study of the mental health consequences of child abuse and neglect; application of the recent advances in psychobiology and behavioral research to disorders of children and adolescents; continued development of new treatments for depressive and manic depressive disorders; early intervention and preventive strategies in a wide range of mental disorders; and the study of the interaction of behavioral and biomedical factors in AIDS.

In contrast to the President's request, our proposal would permit:

- Award of approximately 425 new and competing extramural research project grants, providing needed resources for priority initiatives in schizophrenia, elderly and child mental disorders, and the behavioral factors in the development and treatment of AIDS;
- Award of at least 4 new Research Centers in priority areas such as schizophrenia, child disorders, aging, and neurosciences and funding for the 6 competing renewals terminated under the President's budget;
- Critical increased funding for other research mechanisms such as Small Grants, Research Scientist Development Awards, (which particularly focus on establishing a pool of talented younger investigators) as well as Cooperative Agreements and Contracts;
- Adequate personnel and equipment for the Intramural Research Program.

NIMH COMMUNITY SUPPORT PROGRAM AND OTHER SERVICES DEMONSTRATIONS

(in millions of dollars)

FY '86	Current Services FY '87	President's FY '87	Our Proposal FY '87
$ 12.5[*]	$ 11.0	0	$ 20.0

([*] 11.9 after GRH)

The National Institute of Mental Health (NIMH) Community Support Program (CSP) focuses on the unique problems of individuals with chronic mental illness who are trying to make lives for themselves in the community. Originally designed to serve adults, the program was expanded three years ago to serve children and adolescents who have severe emotional problems. CSP was again expanded in 1984 when P.L. 98-507 charged NIMH with serving homeless and elderly adults with chronic mental illness. Funds are used to stimulate better planning and coordination of state and local programs by providing technical assistance and community based service programs. Success is reflected in the increasing focus of state and local communities on the needs of these individuals, the substantial drop in hospitalization of the target population, the success of demonstration projects and the number of applications to NIMH which continue to exceed available resources.

The President's request is to provide no funds for FY '87. If enacted, it would wipe out this small but effective initiative. The lack of adequate community resources to serve those with chronic mental illness has led to a crisis in many states and contributed to the growing population of homeless people and an alarming growth in the number of teenagers and children, as well as adults, who are committing suicide. Failure to fund CSP demonstration projects will severely curtail the ability of states to overcome the most intractable problems related to this population whose need for assistance grows each year and to better serve deinstitutionalized adults, homeless people with chronic mental illness, children and adolescents with severe emotional problems, and individuals with chronic mental illness who move in and out of the hospital and jail systems. We recommend $20 million for the Community Support Program and other service demonstrations for FY '87.

The recommended amount is necessary: (a) to continue and expand NIMH services research initiatives on problems of homeless people with chronic and other mental disorders and to continue local demonstration projects for providing services for this hard to reach group ($5 million); (b) to continue demonstration projects on the more effective use and coordination of services for elderly persons who suffer from serious mental disorders ($1 million); (c) to plan and initiate demonstration projects to coordinate services for people with mental disorders who are in the jail and hospital systems ($2 million); (d) to continue state-wide CSP initiatives for adults who have chronic mental illness ($4.5 million); (e) to continue and expand the Children and Adolescent Service System Program (CASSP) for children with serious emotional problems ($6.2 million); (f) to continue to conduct important services system research ($1.3 million). The need for more effective planning, development, coordination, outreach and evaluation of services is not only critical, it is mandatory.

MENTAL HEALTH PROTECTION AND ADVOCACY PROGRAM
(in millions of dollars)

FY '86	Current Services FY '87	President's FY '87	Our Proposal FY '87
\$ 10.0*	\$ 10.5	0	\$ 10.5

(* 9.5 after GRH)

The House and Senate conferees have agreed to (S. 974), the Mentally Ill Persons Protection Act which establishes a protection and advocacy system for persons who have "significant mental illness or emotional impairments" and are residents of facilities providing them with care or treatment. Facilities are not further defined in the bill, but according to the accompanying report include: public and private hospitals, nursing homes, group homes and board and care facilities.

The House version of the legislation passed by a vote of 290-84 on January 30. The Senate passed its bill on June 30, 1985 by voice vote. Given the overwhelming bi-partisan support, the President is expected to sign the bill when it reaches his desk in April.

The program provides funds on a formula grant basis to expand the existing state Protection and Advocacy (P&A) System for the developmentally disabled to investigate complaints of abuse and neglect affecting mentally ill people and pursue administrative, legal and other appropriate remedies. The P&A System in each state must have an advisory board of persons expert in mental health issues, with a majority representation of people who have received or are receiving mental health services and their families. The FY '86 Labor, HHS and Education Appropriations Act included \$10 million (\$9.57 million after G/R/H sequestration). The President's budget proposes to rescind the FY '86 appropriations and requests no funds in FY '87. We recommend that Congress reject the FY '86 rescission proposal and appropriate \$10.5 million for FY '87, the authorization level in the House bill.

Hearings conducted by Senator Weicker in 1983 and 1985 and a comprehensive study undertaken by the staff of his Subcommittee on the Handicapped uncovered a pattern of patient abuse and neglect in public psychiatric hospitals of our nation. Similar problems have been revealed in nursing homes and community facilities caring for persons with mental disorders.

Unfortunately, many of the residents of these institutions have been abandoned or have outlived their closest family members. Their well-being has become dependent, in part, on the availability of trained advocates, knowledgeable about the operations of instutions and the rights of residents, who can investigate and remedy through legal and other advocacy techniques situations of gross negligence and abuse.

With the enactment of S. 974, a P&A System will be developed nationwide building on the experience of the P&As and providing cost-effective and nonduplicative services. The FY '86 monies, when available, will be used for planning, start-up, and training outreach and direct services. Fiscal year 1987 will be the first full year of the program's implementation and must be funded at the full authorization level.

(in thousands of dollars)

	FY '86		Current Services FY '87		President's FY '87		Our Proposal FY '87	
	FTE	Amount	FTE	Amount	FTE	Amount	FTE	Amount
NIMH								
Direct Operations	364	$34,675	364	$34,074	364	$31,749	364	$34,074
Research	526		526		526		538	
NIDA								
Direct Operations	175	$16,307	175	$16,976	175	$15,983	180	$18,000
Research	85		85		85		93	
NIAAA								
Direct Operations	110	$11,658	110	$12,135	110	$10,876	125	$13,632
Research	92		92		92		100	

Direct operations activities provide program management of the ADAMHA's research, training and services activities. Adequate staffing and program support are critical for the proper development and implementation of the three Institutes' programs. We are concerned that over the past several years there has been a gradual erosion of funds available for activities which are essential to the support of research in particular. To make full use of its resources, the ADAMHA enterprises must maintain stewardship and oversight over the expenditure of its funds; provide opportunities for its own staff to stay in touch with new developments in the field; and have the ability to disseminate the results of its work. Curtailment of essential travel, publications, and communications expenses can result in the waste or misdirection of tens of millions of dollars.

In contrast to the President's proposal, our proposal would:

- Restore the AIDS research program to the ADAMHA. This program is proposed for transfer to the PHS under the 1987 budget.
- Provide NIMH with needed funds for site visitation and technical assistance to extramural research grantees; critical data gathering activities in the field of mental health statistics and research on delivery systems and health care financing; technical assistance to states and local communities for dealing with the problems of the chronically mentally ill, mentally ill homeless, seriously disturbed children and adolescents and mental disorders affecting the elderly; and research dissemination activities.
- Restore funds to NIDA for prevention and communications activities disproportimately reduced under the recent sequestration order.
- Provide NIAAA with increased funds to maintain program growth and restore postponed initiatives including the National Clearinghouse for Alcohol Information, and high-priority Homeless, Prevention and AIDS-related activities.

June 26, 1985

Dear Members of the Senate and House Appropriations Subcommittee on Labor, Health and Human Services, and Education:

We write as spouses of members of Congress. We are very concerned about the tragedy mental illness brings to individual families and to our nation. We feel that the time is now for declaring war on this ugly and neglected disease. We appeal to you to commit yourselves now to this fight by increasing present research funds for the National Institute of Mental health.

Mental illness strikes anywhere and everywhere. Its causes are unknown and so are its cures. Medications are helpful to many, induce risky effects in others. Adolescents and young adults are the highest at risk groups. Millions of young lives are shattered annually leaving victims unable to become productive citizens. And for each victim there is a shattered family, and society itself has acquired another problem.

Most of the mentally ill are hospitalized for only brief periods when their condition reaches extreme levels. Usually they are somewhere in the community, often with aging parents who are less able to care for them. Many become the homeless street people, drug abusers, and occupants of our jails.

- Ten to fifteen million persons in the United States are affected by severe, disabling mental illness each year.
- Mental illness costs society 67.4 billion dollars each year in medical care, lost productivity and social welfare programs.
- For every cancer patient in the country, the United States government invests two to three hundred dollars in cancer research annually. For every schizophrenia patient, the government invests seven to fourteen dollars.

How unjust that while the cost of mental illness are enormous research into its causes and cures receives less than almost any other major disease. We implore you to change this. We hope you will agree with the compelling reasons we've tried to point out.

Break throughs which will benefit all mankind are ahead, research particularly on the brain holds tremendous promise. We ask subcommittee members to consider increasing the present research funding of the National Institute of Mental Health by nearly one third, and to send a signal that the time is now to declare war and conquer on these devastating diseases.

Sincerely,

Signed by:

Corinne Conte *Jane Denton* *Norma Lagomarsino*

Susan DeConcini *Nancy Domenici* *Catherine Stevens*

AMI

The National
Alliance For
The Mentally Ill

FACT SHEET ON

MENTAL ILLNESS RESEARCH

- Until recently, Federal support for research on mental illness suffered serious erosion in real dollars, shrinking nearly in half between 1967 and 1977. By contrast, funding for research on other illnesses increased at a rate substantially above inflation. While NIH grants were nearly doubling, NIMH grants dropped by about one fourth during the decade of the 1970's.

- A glaring gap remains between our national investment in understanding mental and physical illnesses, in spite of the recent bipartisan efforts to put all health research on an equal footing. To repair past damage, we must accelerate mental illness research funding.

- The Federal government must shoulder the lion's share of the burden because only 15 percent of the mental illness research dollar comes from private sources, compared to 45 percent of the general health research dollar.

- Serious mental illness is a major public health problem: Schizophrenia affects at least 1 percent of the population, major depressive illness 5 percent. Related alcoholism, drug abuse, suicides, homicides and stress-related physical illness loom as major problems for our society.

- The costs of mental illness to the U.S. economy are staggering, with at least **$36** billion annually in *direct* care costs, ***excluding*** alcohol and drug abuse. Schizophrenia alone accounts for 40 percent of all long-term care hospital days, compared to 27 percent for cardiovascular diseases. Moreover, *indirect* costs are enormous, totaling **$67.4** billion. For example, among Social Security Disability benefit days, schizophrenia accounts for 20 percent -- exceeded only by cardiovascular diseases at 27 percent.

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- **In spite of rapid and exciting advances in the brain sciences, their translation into a better understanding and treatment of mental illness is being delayed by the mental illness funding gap. Among Institutes that support brain research, NIMH alone has the ability and the motivation to apply the neurosciences to the special complexities of mental illness.**

- New drugs with fewer side effects can be "engineered" as scientists discover the structure and mechanisms of naturally occuring brain chemical and receptor systems.

- PET scanners and a growing armamentarium of other imaging and mapping technologies are opening "windows" into brain activity of living humans, offering potentially powerful research and diagnostic opportunities.

- Sophisticated molecular genetics and assay techniques are opening the way to development of tests which could permit early identification and treatment of individuals predisposed to serious mental disorder.

- Healthy business enterprises routinely reinvest **4 - 5** percent of their earnings into research and development. Yet we as a nation are investing less and less of our total resources in research -- less and less in our future. As a percentage of our Gross National Product, all R & D has dropped from about **3** percent in the early 1960's to about **2** percent today. This decline has been more precipitous in the area of health. Before the mid 1960's, **2.8** percent of our total health care dollar went to research, compared to only **1.5** percent today. For mental illness, this declining trend has been even more pronounced.

A PROPOSAL

After a thorough evaluation of the needs and opportunities in mental health research, the Institute of Medicine of the National Academy of Sciences last year recommended that funding be increased to **$300** million annually in 1983 dollars. The Institute of Medicine report notes that **"had NIMH just kept pace over the past 12 years with increases in the NIH research budget, its research budget would have grown to $312 million by 1984." The Institute's actual research budget in 1985 was $193 million.**

en to overwhelm society. The people of East Cleveland have nothing to say about what are or are not acceptable living arrangements. The people of New Jersey cannot give preference, in receipt of welfare, to married—as opposed to cohabiting—couples, according to the Court in New Jersey Welfare Rights Organization versus Cahill. The Congress cannot direct food stamps only to households composed of individuals related by blood, marriage, or adoption, according to the Court in USDA versus Moreno.

In short, there are no grounds for the community to impose its values on others. Its notions about family structure or socially productive behavior are entirely relative. Intimidated by that argument, many public officials have, in effect, written off what some call "the underclass," the millions who have been left behind in America's ongoing progress. But we have done them no favor by not imposing our norms upon them. They have paid the price for the relativism of public policy. Their children continue to pay it.

Meanwhile, evidence accumulates that the setting of social standards by government, the official preference for certain kinds of living arrangements and behavior patterns, would be one of the best things we could do for those now trapped outside the American mainstream. Among disadvantaged minorities, intact families have attained incomes near the national average. Among the poor in city after city, youngsters are excelling in schools that are short on resources but rich in moral standards. In experiments with mandatory work programs, welfare dependency has fallen. Sure, the public benefits from these trends. But the persons involved have the greatest gain, not only financially but where it counts most: in their self-respect, their independance, their human fulfillment.

That is reason for great hope, but only if we are willing to translate these lessons into policies which affirm and enforce the norms upon which human advancement depends. That means those in government have a special responsibility. They have an obligation to apply the standards they avow to their official decisions. Otherwise, they are juggling two sets of ethical books, one for private lives and the other for public business. They must not be afraid to act upon the values they profess, to translate into legislation or administration the sense of right and wrong that distinguishes us from the totalitarians of these modern times.●

UNREST AND VIOLENCE IN SOUTH AFRICA

● Mr. SIMON. Mr. President, I take this opportunity to congratulate Bishop Tutu on his appointment as the Archbishop of Capetown. He is the first black man to head the Anglican Church in South Africa. Bishop Tutu is a great man and a formidable spiritual leader of his people. I had the privilege of meeting him when he visited the United States and we discussed the situation in South Africa. Bishop Tutu has repeatedly warned that continued white intransigence would lead to further violence in South Africa. Sadly his predictions have come true. In the 24 hours preceding his election, for example, 14 black persons died and the bodies of another 36 were found in a tribal homeland north of Pretoria.

I am increasingly concerned about the reports of continued heightened violence in South Africa. For a time, the restrictions on the American press imposed under the state of emergency decree issued by the Government in South Africa resulted in less coverage by American media of the violence and unrest in South Africa. Now the State of Emergency has been lifted but the press is still restricted in instances from covering the unrest and violence. But that unrest and violence is still occurring on a massive scale. According to Amnesty International, extensive violations of human rights by the South African authorities have escalated further in the wake of widespread black protest against Apartheid.

Recently, Amnesty International USA published a report that documented that in 1984 238,000 people were arrested because of alleged violation of the pass laws. The State Department's country reports on human rights practices reported that almost 900 people were killed last year and more than 11,000 were detained by the police and security forces there.

We are at a crossroads in our policy toward South Africa. We cannot stand idly by and tacitly participate in the South African economy by accepting the President's assurances that the sanctions in his Executive order are sufficient. We must take additional measures to promote justice and freedom in South Africa. That is why I recently introduced a bill for further economic sanctions against South Africa and why I intend to support other similar measures as they come before Congress.

Two weeks ago, Archbishop Tutu risked a charge of treason by saying:

> I have no hope for change from this government unless they are forced. We face a catastrophe in the land, and only the action of the international community, by applying pressure, can save us. Our children are dying. Our land is burning and bleeding, and so I call on the international community to apply punitive sanctions against the government to help us establish a new South Africa—nonracial, democratic, participatory and just.

Today I congratulate Bishop Tutu on his election, and I say to him that we in the Senate hear his call and the call of millions of other South Africans. We can answer that call by bringing to the floor of this body more stringent sanctions legislation and voting that legislation into law.●

SESQUICENTENNIAL EDITION OF THE EDGEFIELD ADVERTISER

● Mr. HOLLINGS. Mr. President, I should like to recognize a great achievement by the Edgefield Advertiser, a weekly newspaper in Edgefield, SC. This newspaper is currently celebrating its sesquicentennial anniversary. In the 150 years in which this newspaper has been in operation, it has never missed an issue or changed its name. In fact, for the past 114 years, it has been owned by the same family.

The history of the Edgefield Advertiser is filled with colorful and historic stories. For example, it was the only newspaper to publish the letter of Colonel Travis, commander of the Alamo, to Gen. Sam Houston. This historic press coverage prompted the Governor of Texas and the mayor of San Antonio to send their congratulations to the Edgefield Advertiser in commemoration of its sesquicentennial.

The Edgefield Advertiser combines a strong sense of history with a dedication to excellence in reporting the events that currently impact on Edgefield and the surrounding area. I offer my most sincere congratulations on a job well done.●

NAUM AND INNA MEIMAN: SUPPORT IN CONGRESS

● Mr. SIMON. Mr. President, I just returned from a moving news conference to demonstrate solidarity with Naum and Inna Meiman with Senator HART, Congressman WIRTH, Congressman SIKORSKI, Lisa Paul, Olga Plam, Naum's daughter, and others.

All of us spoke about the profound effect that Naum and Inna had on us when we met them. As Lisa Paul, a young Minnesota woman who went on a 25-day hunger strike for the Meimans, said, "The Meimans have this incredible energy and vitality." To think of Inna suffering in pain in Moscow is a chilling thought. Naum is a 74-year-old man. He has not performed "sensitive" work in 30 years.

The Meimans are persecuted for expressing their desire to leave the Soviet Union. What good does it do the Soviets to keep the Meimans there?

I strongly urge the Soviets to allow the Meimans to emigrate to Israel.●

SCHIZOPHRENIA

● Mr. DOMENICI. Mr. President, schizophrenia strikes 1 percent of the American people. It is devastating disease. Of the hundreds of thousands of homeless Americans, from one-third to one-half are mentally ill, most of these afflicted with incurable schizophrenia. The costs of this disease to this nation annually exceed $20 billion. We are now spending $27 million annually on research.

Science tells us it is a brain disease, that is does not come about from bad parents or "toxic" families. Nor is it necessarily character flaw in the afflicted person, as it was once believed. Because of psychotropic medication, schizophrenic citizens are no longer hospitalized for endless years. They are stabilized and returned to the community. Unfortunately, communities are poorly prepared to receive them and to provide the rehabilitation services that can and will help them achieve their potential for independence and self-care.

The care givers today are, in the majority of cases, the families. They need help in understanding the illness, in providing a therapeutic environment in the home, in financial support, and in respite from the day-in-day-out regime of care.

Mr. President, these remarks are to introduce an excellent four-part series on schizophrenia that appeared in the New York Times, March 16-19, 1986. I offer them because there is a lot of ignorance across this land about schizophrenia, as well as other serious mental illnesses such as major or manic depression. The Times series gives an up-to-date report of the state of scientific research on this disease. It details the emerging family movement that is achieving historic growth as a force in the Halls of Congress, our State capitals, city halls, and courthouse. It describes the treatment and rehabilitation needs of these mentally ill citizens. It describes the gaps in our mental health system.

I commend the editors of the New York Times for focusing on this important topic at a time when policymakers must face the consequences of mental illness in our society, particularly among the homeless whose numbers continue to grow.

I ask that the articles from the New York Times be printed in the RECORD.

The articles follow:

SCHIZOPHRENIA PUZZLE: TOLL RISES AMID HOPE

(By Philip M. Boffey)

WASHINGTON.—Schizophrenia is emerging as the worst mental health problem facing the nation. Yet it has long been the most neglected.

Never before in American history have so many schizophrenics been seen on the streets of American cities, screaming aloud to voices only they can hear, proclaiming themselves God, warning passers-by that the Central Intelligence Agency has bugged their brains, or simply sitting, mute and withdrawn, sunk in an apathy so deep that no emotion crosses their faces.

But street people are only a part of the problem. Far more victims of this shattering disease are now in the homes of their families, in the nation's hospitals, in nursing homes, halfway houses or seedy hotels—either forgotten or given care that, health experts agree, has brought only limited relief of their suffering.

SIGNS OF NEW UNDERSTANDING

But there are now important signs of change.

Interviews and an extensive review of medical journals and scientific papers reveal that the nation is moving toward a new era in both understanding and treating schizophrenia. The new insights are paradoxical, the news, to some degree, both bad and good:

Not only are more people suffering from schizophrenia than ever, but medical and behavioral scientists believe that the disease itself is far more complicated and resistant to treatment than had been realized. Moreover, though much has been learned about its manifestations, the basic cause remains a mystery.

On the other hand, for the first time in decades, scientists are expressing cautious hope that progress can now be made toward unraveling the inner mysteries of schizophrenia and finding more effective treatments.

ENORMOUS COST TO SOCIETY

All told, two million to three million Americans, 1 percent of the population, either have the disorder or will develop it at some point in their lives, according to the National Institute of Mental Health.

The cost to society is enormous, with authoritative estimates ranging from $20 billion annually, as calculated by the N.I.M.H., to $48 billion reported by the Institute of Medicine of the National Academy of Sciences. The estimates are of expenses incurred in providing treatment and social services, as well as the staggering amount of productivity lost as schizophrenics; lives are disrupted.

"While schizophrenia is by no means the most common mental illness," a 1984 report from the mental health institute asserted, "It is probably the most costly and devastating in terms of human suffering."

It has never been easy to determine who is schizophrenic; all the homeless people who wander the streets are by no means suffering from the disorder. But the N.I.M.H. studies were based on one of the most scientifically precise analyses ever conducted of schizophrenia.

Some 20,000 people were randomly selected by researchers at Yale, Johns Hopkins, Washington University of St. Louis, Duke and the University of California at Los Angeles, and carefully chosen diagnostic criteria were used to determine which could properly be judged to be suffering from the disorder. Information was collected from the late 1970's until late 1981; over the next three years it was analyzed and extrapolations were made to the general population.

Schizophrenia is the classic disease of madness, a disease that can produce symptoms and behavior so bizarre that people recoil from its victims in fear, revulsion or disbelief.

Schizophrenics often suffer from delusions, hallucinations or a wild disordering of thought processes, an inability to think straight. In periods when their more florid symptoms are absent, they may show no emotion at all, talking in a flat, monotonous voice, from a face without expression, showing almost no response at all to the people and events around them. Then again, at other times, the patient may show no signs of disorder.

The reasons for all this remain a mystery. Schizophrenia is still regarded as one of the most baffling of all—"possibily the most complex puzzle in biomedicine," according to Dr. Shervert H. Frazier, the director of the National Institute of Mental Health. Its cause is unknown, its progression unpredictable. Schizophrenia has no cure, although drugs can control its most bizarre manifestations. Nor is there any laboratory test capable of providing an undistputed diagnosis.

But rapid strides have been made in understanding some aspects of the disease, producing a small revolution in scientific comprehension and guarded hope for further advances. The new studies have shown that the outlook for schizophrenics is by no means as uniformly dismal as was widely believed just a few years ago. Roughly half of all schizophrenics eventually get better, spontaneously, over the course of decades, according to five recent studies.

Many other key concepts about the disease have changed dramatically as well. The old notion that families were to blame for causing the disease has given way to the notion that biological factors play a major causative role.

There is a recognition now, too, that drugs, introduced in the late 1950's, are not by themselves enough—that psychotherapies and drugs work best in tandem. And in long-term care, simple management of daily life is proving as important as drugs or psychotherapy. Most important, old beliefs have faded that the disturbing outward symptoms, the hallucinations and delusions, are the most important aspect of the disease. Less flamboyant "deficit" symptoms, like apathy and inertia, are now regarded by many experts as constituting the care of the disorder.

Scientists have thus realized, belatedly, that they were focusing much of their energies for the past three decades on the less important symptoms.

ANCIENT MADNESS OR A MODERN ILL?

Nobody really knows whether schizophrenia is an ancient disease that has always afflicted mankind, or an illness that was ushered in by modern civilization. The word "schizophrenia" was not even coined until 1911, and scholars still argue over whether symptoms of madness described in earlier literature represent essentially the same disorder that we now call schizophrenia.

Dr. E. Fuller Torrey, a Washington psychiatrist who has published some of the most provocative analyses of the origins of schizophrenia, believes that the illness was virtually unknown until about 1800, when it appeared suddenly all over the Western world, increased rapidly for about 100 years, then leveled off about 1920 and has maintained essentially the same prevalence rate ever since. He links the appearance and spread of schizophrenia to the rise of civilization. But Dr. Torrey acknowledges that his is a minority view.

The mainstream view was expressed in a paper by four scholars from N.I.M.H., published in a recent issue of Comprehensive Psychiatry. They found sketchy descriptions of delusions, auditory hallucinations and bizarre behavior in documents as far back as the third millenium B.C., in cuneiform tablets from ancient Mesopotamia. Although "the evidence is not conclusive," they said, it nevertheless suggests that "schizophrenia has existed throughout history."

Dr. Torrey, who has conducted some of the most thorough epidemiological reviews, believes that the highest schizophrenia rates in the world are found in northern Sweden, western Ireland and northern Yugoslavia. The United States falls somewhere in the middle, with rates roughly comparable to those in Japan, England, Germany and Denmark. And relatively low rates are found in southern Europe and in the developing world.

But such comparisons are fraught with uncertainty. Schizophrenia has been defined solely by its symptoms, and doctors in different countries have often used different definitions or methods of diagnosis. Whatever real differences may exist are not understood.

In a majority of countries surveyed, schizophrenia appears to be disproportionately high in the poorer classes. But it is not known whether the disease actually strikes the poor in greater numbers, or whether the afflicted poor are more visible or more often diagnosed with what may be a stigmatizing label. And schizophrenia often so disables its victims that they are unable to earn a living.

Schizophrenia is apparently not becoming more prevalent as a percentage of the population. Epidemiologists have long estimated that about 1 in every 100 Americans will develop schizophrenia at some point in their lifetime, and they believe that rate is holding stable. But as the nation's population increases, particularly in the age groups where schizophrenia is most common, the number of schizophrenics in the United States has climbed to an all-time high.

The mental, emotional and financial toll exacted by this bizarre disease is enormous. Schizophrenics occupy over half of the hospital beds for the mentally ill and retarded in the United States and fully one-fourth of all hospital beds in the nation, according to the Institute of Medicine.

Few other mental illnesses disrupt the whole course of their victim's lives so completely. Schizophrenia typically strikes men in their late teens or 20's, and women perhaps five years later, just at the point where the victims have finished the long, costly preparation for life and are embarking on adulthood. For reasons that are unclear, but could be related to hormones, the course of the disease is often less severe in women.

NEW THOUGHTS ON CAUSE AND RECOVERY

The old rule of thumb used to be that about a third of all schizophrenics would improve, about a third would stagnate and a third would deteriorate. Indeed, a recent diagnostic manual published by the American Psychiatric Association, known as DSM-III, says "a complete return to premorbid functioning is unusual—so rare, in fact, that some clinicians would question the diagnosis."

But recent studies have shown surprising and encouraging evidence that many cases of schizophrenia eventually cure themselves.

A recent long-term follow-up of 118 schizophrenics who were discharged from Vermont State Hospital 20 to 25 years found that half to two-thirds had since achieved "significant improvement or recovery." The improvements seemed to be spontaneous, for the most part coming well after treatment. Fully 45 percent had no psychiatric symptoms at all after two decades, and another 23 percent had lost all symptoms of schizophrenia while developing symptoms of other, more treatable, mental disorders. The results corroborated similar results from three European studies and another American study over the past decade indicating that half or more of the schizophrenics eventually recovered or significantly improved.

"It's not all downhill," says Dr. Frazier, the N.I.M.H. director. "Our data show that 50 per cent or more do improve."

"They get better but not necessarily well," says Dr. Howard Goldman, a special consultant to the institute. "It's a far better prognosis than we used to give people, that they would just get worse and worse and end up on the back wards of the state hospital as a vegetable."

Theories as to what causes schizophrenia have changed sharply over the years, although they remain just that—theories. Those tracing the cause of schizophrenia to family or childhood experiences, although once very popular in this country, have faded in recent years. The old concept that "schizophrenigenic mothers" caused the disease by their coldness and rejection of their children has largely been abandoned, as have notions that pathological family interaction was the chief cause.

But stress within the family is still believed to play some role. Studies in several countries have found that schizophrenics who returned after hospital treatment to live with families that criticized them a lot or got overinvolved in their lives suffered far more relapses than those who returned to families more tolerant and supportive.

Moreover, stress in general is still believed by some experts to play a role in triggering schizophrenia, perhaps by pushing a vulnerable individual over the edge.

But today, most scientists are focusing on possible biological or medical causes.

Genetic factors clearly play some role, according to a range of research done years ago and refined in more recent studies. The children of a schizophrenic parent, for example, have about a 10 percent chance of developing schizophrenia, and of two schizophrenic parents a 39 percent chance, far above the 1 percent chance in the general population. Most scientists believe that what is inherited is not the disease itself, but a vulnerability or predisposition to it. No one, however, has pinpointed a specific genetic defect responsible.

EMPHASIS SHIFTS TO OTHER SYMPTOMS

Technologies that enable scientists to probe deeper than ever into the structure and functioning of the brain have given an impetus to the search for biochemical and physiological abnormalities.

New brain scanning instruments have shown that the brains of some schizophrenics are actually different from the brains of people who do not have the disease. Schizophrenics often have an enlargement of cavities in the interior of the brain, or functional abnormalities like unusual electrical impulses, decreased blood flow or glucose utilization in key areas of the brain, and excess or lack of neurotransmitters, the cells of the brain that enable it to send and receive information.

Nobody knows what role these biological factors play in causing schizophrenia, and no common biological factor has yet been found. But the rapid rush of new findings is creating optimism that a biological explanation will eventually be developed.

One theory is that schizophrenia will be shown to be caused by a slow virus, exerting its effect years after it first invades the body. The evidence, however, is still sparse.

The new understanding of schizophrenia has placed a major emphasis on a range of less glaring symptoms that had previously received little attention. Among these are the blunting of the emotions, loss of curiosity, narrowing of ideas, poverty of speech, a diminution of social drive, and deep apathy or inertia. For several decades, the features most commonly emphasized by doctors, those now referred to as the positive ones, have been the bizarre manifestations like hallucinations, delusions and incoherent thoughts.

The positive symptoms are often accompanied by the less dramatic, but equally debilitating, negative symptoms. Sometimes they are closely linked, and both sets of symptoms come and go in tandem, according to William Carpenter, a psychiatrist at the University of Maryland who initially identified the importance of the negative symptoms.

But in many cases, the negative symptoms appear to be entirely independent of the positive symptoms, so that a patient can be "cured" of hallucinations and delusions but remain deeply impaired by apathy.

"Most treatment has focused on the positive symptoms in an effort to reduce the hallucinations and delusions and the more florid aspects of the illness," said Dr. Joseph Autry, director of policy analysis for N.I.M.H. "Now we need to address the deficits that may, in fact, be the core element of the disease."

"There is a concern that while the deficit, or negative, symptoms may be the most troubling, the bulk of attention in diagnosis and treatment has been directed toward the positive symptoms," Dr. Frazier said in a speech last November. "This stems, in part, from the fact that existing medications are more effective in treating positive symptoms."

DRUGS ARE A HELP, NOT THE ENTIRE ANSWER

A major breakthrough in treating schizophrenia came three decades ago with the discovery of the antipsychotic, or neuroleptic, drugs, found accidentally during a search for medication to alleviate anxiety among surgical patients.

The neuroleptic drugs revolutionized the treatment of schizophrenia and had an immense social impact. The drugs control the most disruptive symptoms of schizophrenia, and doctors, for the first time, felt safe in moving patients out of state hospitals and back into the community.

But the drugs do not work on all schizophrenics, and many patients suffer relapses while on treatment. Some 40 percent of all schizophrenics who are discharged from the hospital suffer relapses within two years, even with continued drug treatment, although the number soars to 80 percent if drugs are discontinued. The drugs do not prevent relapses, most experts say, but rather reduce their frequency.

Unfortunately, they can also do damage. Some 13 per cent of all schizophenics who have received antipsychotic drugs for many years develop a side effect, tardive dyskinesia, which can produce involuntary movements of the tongue mouth or limbs.

The initial drug discoveries have not been followed by any comparable advances over the past three decades. What new drugs there are operate in basically the same way and represent, at best, marginal improvements for some patients.

"The basic problem with drugs is that we don't know the cause of schizophrenia, and until we do it's difficult to design a proper treatment," says Dr. Richard Wyatt, head of the neuropsychiatry branch at the National Institute of Mental Health.

Most important of all, the drugs have almost no value in treating the negative symptoms. "I see nothing on the near horizon to treat the deficits with," says Dr. Wyatt. "It would be blind luck if we stumbled across something."

An early approach to psychotherapy with schizophrenics, which involved an intense encounter between therapist and patient, has fallen out of favor. At many private hospitals, though, psychoanalytic and other therapies are used, as well as a more general supportive treatment that tries to build on whatever strengths the patient may have in the midst of his illness. Such therapy is not available to the vast majority of schizophrenics who are being treated in public facilities.

"Almost everyone who does therapy with schizophrenics uses drugs to make the patient accessible to treatment," said Mortimer Ostow, a psychiatrist who wrote one of the first books on combining drug and psychotherapy approaches. "When the patient is too psychotic, with flamboyant symptoms, there is no point in trying therapy."

Current research is seeking ways to lower the dosages of drugs used. Helping patients better organize and order the tasks of day-to-day life has, in early studies, shown promise, allowing lower drug dosages by lessening symptoms exacerbated by stress.

STUDY OF DISEASE HAS BEEN NEGLECTED

Despite its destructive impact and enormous cost to society, schizophrenia has been widely neglected even among those in the position to help.

Psychiatrists in private practice seldom deal with these patients because they are hard to treat and are generally too poor to pay their own way or to carry substantial insurance.

Dr. Torrey scornfully accuses his fellow psychiatrists of ignoring schizophrenics and caring only for what he calls the "worried well"—"neurotic ladies and gentlemen" who spend hours explaining "how their feelings about mother had shaped their lives." Dr. John A. Talbott, a past president of the American Psychiatric Association, acknowledges that psychiatry is "one of the few specialties where the most skilled practitioners take care of the least impaired patients."

The very institutions that are designed to care for schizophrenics often throw up their hands in despair over the great numbers who need help and the lack to date of any really effective treatment to restore their health. Wave after wave of reform in the American mental health system has brought little benefit to schizophrenics. The state mental hospitals, which were created in the last century to provide the first humane treatment for the insane, did little for schizophrenics except lock them up, far from the eyes of other citizens who might be offended by their presence.

The community mental health centers that were supposed to replace state hospitals as the cornerstone of this generation's effort to "reform" mental health care have often neglected the schizophrenics and concentrated on easier patients.

"The history of the care of the mentally ill in this country is one of abuse and neglect," says Dr. Ellen Bassuk, associate professor of Psychiatry at the Harvard Medical School. "Whether that abuse and neglect occurred in the hospital or in the community is beside the point. There's been a lack of commitment to the care of these terribly ill individuals. That's the bottom line."

Research scientists have been reluctant to investigate schizophrenia, largely because it is so hard to understand, measure and treat.

A meeting of expert consultants who were called upon to address the problem at N.I.M.H. last July heard Dr. Frazier express "deep concern" about the difficulties in attracting scientists into the field. Various experts noted a sharp drop in the number of scientific articles on schizophrenia, a drop in applications for research support to a major private foundation, and a loss of interest among young scientists. A host of factors were blamed for the decline, including the lack of any comprehensive theory of the disease to guide research, the apparent intractability of the problem and the limited possibilities to actually help many patients.

But signs of a stronger Federal commitment to conquer schizophrenia are emerging. Dr. Frazier said that two years ago he felt that "inadequate attention" was being paid to schizophrenia in comparison to other mental illnesses and that people in the field had "lost heart," so he pushed for a stronger emphasis on studying the disease.

The N.I.M.H. recently selected schizophrenia as one of its five major targets, elevating it to a new level of importance. The agency's funds for research have been edging up slowly, from $18.4 million in the fiscal year 1985 to a projected $20.6 million this year, although critics feel these sums are paltry given the importance of the disease. And the agency has established a new schizophrenia research branch to coordinate and focus attention on the disorder. It is also considering a broad range of incentives to attract young scientists into the field.

No one believes that a cure for schizophrenia is near, but Federal officials are increasingly optimistic that major progress can be made. So is Dr. Torrey, who sees "a potential for significant breakthroughs" if research is increased. "Ten years ago we felt we didn't know where to begin," he said. "But given rapid advances since then, it looks very promising now. To not invest in schizophrenia research is very foolish."

SCHIZOPHRENIA: DISORDER HAS MANY FACES

The roots of schizophrenia remain a mystery. There is uncertainty as to the precise roles of biology and of environment, and many experts believe that the diagnosis of schizophrenia covers a group of disorders that will one day prove to have differing causes.

The diagnosis of schizophrenia requires that a person display a serious loss of contact with reality, such as bizarre delusions—for example, that one's thoughts are being broadcast on the radio—auditory hallucinations, or incoherent thoughts with no awareness of the incoherence. These symptoms typically accompany a marked deterioration of the person's ability to function.

When these active symptoms clear up, there are residual signs of schizophrenia that can linger for years. These include markedly peculiar behavior, like talking to oneself in public; social withdrawal and an inability to function as well as previously, and odd ways of speaking and thinking. Experts now say that long-term care is often needed for long-lasting and subtle deficiencies, such as apathy and lack of normal feelings.

There are, by Federal estimates, more than two million Americans who could now be diagnosed as schizophrenic, and over 600,000 of these are in active treatment in a given year. Another half million to a million schizophrenics are being cared for in a range of settings, with their families, in boarding houses or nursing homes, or on their own, many living in the streets.

There are several types of schizophrenia, depending on which symptoms predominate. A "disorganized" diagnosis is made when the person is often incoherent but has no systematic delusions. "Paranoid" is the diagnosis when the person has delusions of persecution or grandiosity. When there are no prominent psychotic symptoms but the person's behavior is deficient in many regards—withdrawn and eccentric, for example—the diagnosis is a "residual" type of schizophrenia.

Schizophrenia typically begins in late adolescence or early adulthood; it generally first emerges before the age of 45.

There are two general patterns of symptoms, one thought to have a good prognosis, the other poor. One pattern, sometimes called "reactive" schizophrenia, begins in early adulthood with a sudden, extreme psychosis that typically clears up within six months, leaving no further problems. In "process" schizophrenia there are signs of trouble early in life, with the first full psychotic symptoms emerging in adolescence and often continuing in episodes throughout life.

But there is no single, set course schizophrenia follows. It has been thought that about one-third of schizophrenics suffer a single acute episode and never have a further problem. Another third have longer lasting symptoms, which finally clear up entirely, or enough to allow a normal life. And the final third have symptoms all their lives, at times increasing in severity, although schizophrenia seems, generally, to lessen gradually over the years.

The common belief that schizophrenia involves a "split personality" is a misconception. Multiple personality is a psychiatric disorder that is clinically distinct from schizophrenia.

SCHIZOPHRENIA'S VICTIMS INCLUDE STRAINED FAMILIES

(By Eric Eckholm)

The greatest numbers of schizophrenics do not now live in hospitals or in the streets or jails, but rather with their families, representing a profound change in the way the nation cares for its most severely mentally ill.

The families, many health officials have only recently concluded, are forgotten victims of this baffling disorder that disables one of every hundred Americans at some point in their lives.

Parents and siblings of schizophrenics say they are racked by demands that would overtax a Mother Theresa. They describe themselves as bitter, despairing and wrung out.

FAMILIES BECOME THE DOCTORS

Between the excruciating turbulence at home and the limited services they receive from public agencies, families become "lost in a process that is hideously engulfing," as one woman with a schizophrenic niece described it.

"The families have become the doctors, the nurses and the social workers," said Dr. John Talbott, former president of the American Psychiatric Association. Close to a million families are struggling with these burdens of schizophrenia, whose victims can suffer a serious loss of contact with reality leading to delusions, incoherent thoughts, bizarre behavior or a profound withdrawal and apathy.

A generation ago, a person diagnosed as a chronic schizophrenic was apt to live and die in a state hosptial. Since the 1950's, however, with the discovery of antipsychotic drugs and changes in social attitudes, far fewer have been permanently kept in institutions. Instead, they tend to stay in the hospital only temporarily, during acute breakdowns, and then return home with little or no medical follow-up.

The dazed man huddled on the sidewalk, the babbling woman with an overstuffed shopping bag have come to symbolize the "deinstitutionalized" schizophrenic.

Yet in fact, some 65 percent of patients discharged from mental hospitals return to their families, usually their parents, according to the National Institute of Mental Health. An estimated 800,000 schizophrenics now live with their families and many more live nearby, depending on relatives for crucial support. But society has, for the most part, left these caretakers to fend for themselves.

An index of their suffering, borne silently until recently, is the explosive emergence around the country of activism on the part of families of the mentally disturbed: The National Alliance for the Mentally Ill is one of the nation's fastest-growing pressure groups.

The goals of this "family movement" are emotional support, public education and advocacy of neglected programs and research on severe mental diseases, schizophrenia foremost among them. It was formed in 1979 at a meeting attended by delegates from 80 local family groups. Now, just seven years later, it includes 550 groups from every state, with members drawn from 30,000 households. Throughout the second half of 1985 local groups were joining the alliance at a rate of 4 per week.

It is not only the families who will pay, activisits warn, if society does not help mental patients live more independently. Schizophrenia tends to strike people in their late teens or 20's, but now, as the first generation of nonhospitalized patients ages, more and more elderly parents find themselves caring for middle-aged schizophrenic children.

"I predict we'll see a new wave of people living in the streets as their parents pass away," said James W. Howe, the president of the burgeoning national alliance, with headquarters in Arlington, Va. "I'm not arguing they should be back in hospitals. There's an urgent-need for residences, job programs and other community services."

Mental illness can devastate a household financially as well as emotionally. Many patients are diagnosed as schizophrenic in their teens and then live 60 years, in and out of hospital and home, without ever working.

"It has ruined families economically," Dr. Talbott said. "People come to me saying, 'I've got $40,000 left and a 40-year-old schizophrenic child. What should I do?'

"I don't know what to tell them," he admitted.

Stung by the stigma of mental illness, the families of schizophrenics often turn inward, spending years in anguished isolation.

"A stigma is society's way of telling people they somehow have failed," said Phyllis Vine, a historian at Sarah Lawrence College whose experiences with a schizophrenic niece led her to write a book called "Families in Pain."

The truth is concealed from neighbors, even relatives. Outside friendships tend to wither as the family struggles against the strange specter in the home.

BURDENED FAMILIES 'FIND EACH OTHER'

Mr. Howe and his wife, Carol, of Garett Park, Md., say their experience was typical. For seven years after one son, then another, became mentally ill, they "wandered alone," as Mr. Howe described it. "We paid people $75 an hour to tell us it was our fault. We believed them and that kept us in the closet.

"We felt guilty, frustrated and angry," he continued. Then in 1978, five families with similar problems "found each other," he said. "That gave us exquisite relief—we learned we weren't alone, and that we could restore some sort of order to our lives."

Activists say that families have become more willing to declare themselves publicly as they learn about the changing scientific understanding of schizophrenia, about the decline in theories that blamed domineering mothers or family strains for what is now seen as a disease with biological origins.

"The old philosophy was that parents, especially mothers, caused their kids to become schizophrenic," said Dr. Talbott. "Now we see that when a kid is this crazy, he'll make the family begin to seem crazy." A growing number of doctors work with families, not so much to treat the "cause" of the child's disease as to help reduce conflict and discourage any family interactions that encourage the schizophrenic symptoms.

Life with a schizophrenic is "endlessly frustrating, a roller coaster," said Dr. Vine. "You can never presume tomorrow will be like today. You constantly steel yourself for the unknown, and you never know when the unknown will hit."

Parents tell of helplessly watching a child become tormented by delusions, become unable to respond normally or cope with daily challenges. But even a parent's love and patience, many admit, can be sorely tested by behavior that seems hostile or uncooperative.

To the frustration of those around them, more than half of all schizophrenics fail to take their prescribed antipsychotic drugs, which for many help normalize thoughts and stave off relapses. Some housemates may suspect the patient is taking advantage of his condition, asserting independence when convenient yet demanding care when needed.

"A parent has to watch a 30-year-old son say he's going out to drink with friends tonight, knowing he might come home psychotic," said Dr. Bert Pepper, the director of the Rockland County Mental Health Center in New York who is an expert on young, chronic mental cases. Quite often, mental disease is exacerbated by the patient's overuse of alcohol or illegal drugs.

LAWS ON COMMITMENT CAN BE A HINDRANCE

While acknowledging that former laws governing forcible hospital commitment were open to abuse, many family activists believe that necessary hospitalizations are now impeded. Even patient who request admission may be turned away by state hospitals if their mental state is deemed insufficiently serious.

When relatives know a patient is having a psychotic relapse but he refuses to acknowledge it, they may reluctantly seek to force him into a hospital. But today's state laws, which forbid involuntary commitment unless a judge is convinced that the patient poses a clear danger to himself or others, are too rigid, many parents assert. Parents describe the wrenching humiliation of appearing in an open courtroom to argue that their child needs temporary hospitalization, sometimes with a public lawyer arguing against them in the child's behalf.

While no statistics on divorce rates have been gathered, psychiatrists say that the stresses of coping with schizophrenic children have taken a heavy toll on marriages. Brothers and sisters, too, tend to suffer, often feeling neglected, angry and guilty. Like their parents, they often lose friends, whom they are embarrassed to bring home.

Often the mothers carry the heaviest loads. In a familiar syndrome, the mother accepts the child's condition as an illness while the father persists in seeing it as misbehavior requiring discipline. "It's not at all uncommon for the father to segregate himself from the problem," Mr. Howe said. "We see a lot of women attending support-group meetings whose husbands refuse to come, or have left them."

Some mothers or other relatives, afraid to leave an unstable patient alone, say they feel like jailers. Unable or unwilling to hire an outside caretaker, they become prisoners themselves.

While Social Security and other government programs help with subsistence and medical expenses, neither these nor private insurance tends to pay all the enormous costs of hospitalization and psychiatric care. Adding to the costs, sometimes a relative must stop working in order to care for the patient, chauffeur him to his appointments and keep watch at home.

At a recent conference, a father summarized his medical expenses over the nine years since his son was diagnosed as schizophrenic, during which the son had been hospitalized 10 times for a total of a 68 months. The medical bills totalled $721,500, of which insurance companies paid $541,000 and the family paid $180,000.

STRAINS ARE HARDEST FOR THE POOR

Once family members join a support group, a transition from "just sharing tales of woe," as one put it, to political advocacy is common.

"At first, I would stay home and cry, and hope he would get better next year," said Kathleen Giaimo of Queens, the mother of a schizophrenic son. "In 1979 I heard about another mother. I called her and we talked on the phone for four hours."

Then, Mrs. Giaimo said, she realized that her son's problem would not disappear and that the family alone could do little. "I got involved with a group to try to make the system change," she said, "because the system stinks."

Mrs. Giaimo became active in Friends and Advocates of the Mentally Ill, in which 500 New York City families now participate. Thirty such groups have sprung up in the state and the movement is "growing like crazy" as more families discover it, said Mrs. Giaimo, who is serving as president of the local association this year.

The strains on the family are all the worse among the poor, who for unclear reasons seem to suffer the highest incidence of schizophrenia.

"A schizophrenic creates even more wear and tear in poor families than in the middle class," said Dr. Neal Cohen of Gouverneur Hospital on Manhattan's Lower East Side. "The family structure is often more vulnerable and can more quickly break apart."

Dr. Cohen said that many young schizophrenics in the inner city start out living with their families, then drift away, often getting into trouble with the police. Sometimes parents give up in despair and break all ties. "We think of these youths as the pre-homeless population," he said.

"The urban poor are facing tremendous burdens anyway, survival issues like housing and income and safety," observed Dr. Donald Brown, the director of the Morrisania Neighborhood Family Care Center in an impoverished area of the Bronx. "We can't count on things we take for granted elsewhere, such as a parent's ability to cooperate with their child's treatment or even visit a clinic. A family member might be unable to come out for strong reasons; work, no baby sitter, fear of leaving the apartment at night."

The volatile mixture of mental illness and drug abuse may also be more common in the inner city, where drugs are readily available. "We're seeing more and more patients confused by marijuana and angel dust," Dr. Brown said of his clinic in the South Bronx. "It's getting hard to find a pure schizophrenic anymore."

SOME PSYCHIATRISTS STILL BLAME FAMILIES

On top of all the other burdens, families often also suffer at the hands of psychiatrists. Many doctors, they charge, have not kept pace with scientific research and still tend to blame the family somehow for causing the disease.

Some psychiatrists acknowledge the problem. "In the past, the families were looked at as noxious agents instead of people with a sick child," Dr. Pepper said. "Many of the parents have been scarred and humiliated by the mental health professionals, especially if their child became ill 15 or 20 years ago."

Local family groups share information about which doctors their members have found to be helpful and sympathetic and which ones they have not. Many groups are also campaigning against what they say are widespread misconceptions about mental illness. Especially pernicious is the image of schizophrenics as prone to violence, a myth sustained, family advocates contend, by frequent portrayals of wild "crazies" on television.

At the national level, advocates are pushing hard for an increase in research on the causes and treatment of mental disorders, now budgeted at about $200 million a year and declining. Of this, about $21 million is specifically allocated for research on schizophrenia.

"Given the costs to society of mental illness, it's unbelievable how little investment in research there is," said Richard T. Greer, the director of government relations for the national alliance. "And this at a time when the biomedical opportunities are so exciting."

Looking to the future, groups in several states are pioneering in the creation of trust funds and corporations that can take over from the parents when they die, providing private case-workers who can keep tabs on the patients and help them procure housing, medical care and other needs.

Meanwhile, a primary goal is to create more programs that can help patients live on their own or in residences where they receive counseling and companionship. For many reasons, a rising number of experts contend, care at home is often not preferable even when the family is willing and able to provide it. For one thing, the parent's home is a poor environment for developing independence, vital if the patient is to regain anything close to a normal life.

Also, the stress for family members is often simply overwhelming, with the result that several lives are ruined by one person's illness. Medical professionals complain of "burnout" from working with patients just 40 hours a week, activists observe. But a family keeping a schizophrenic at home is, in effect, on duty 168 hours a week, with no vacation.

And finally, the parents are deeply aware of their own aging. Many wonder, fearfully, how their ill child will get by 20, 30 and 40 years from now.

"This is what haunts the parents," Mr. Howe said. "What will happen when I'm no longer around? This may be the biggest driving force behind the activism for community services."

Schizophrenia Focus Shifts to Dramatic Changes in Brain

(By Harold M. Schmeck Jr.)

The architecture and chemistry of the brains of schizophrenics can be actually different from those of normal people, new studies show. As a result, a revolution in psychiatry has occurred in which biology has become the main focus of the research on this most devastating and intractable disease of the mind.

Among the most dramatic differences revealed in the new research are computer generated images of the brain that light up in vital regions when a normal person tackles a mental problem. These regions stay ominously dim when the disordered mind of the schizophrenic takes the same test.

Physical brain abnormalities have long been suspected among schizophrenics but have only recently been pinned down by researchers using new tools for exploring the brain.

The brains of some schizophrenics have even been found to weigh less than normal and sometimes look as though the crucial fore part of the cerebral cortex, the "thinking" part of the brain, has atrophied. Abnormalities have been detected in the brain's chemistry as well as structure.

Just how these aberrations account for the hallucinations, the voices and the schizophrenic's chaotic attitude toward the world, however, are still a mystery. Penetrating that mystery, scientists hope, will lead to more effective diagnosis and treatment of the baffling disorder.

What looks like atrophy of the cortex and other physical abnormalities have been confirmed by more than 30 studies, said Dr. Richard J. Wyatt of the National Institute of Mental Health and St. Elizabeths Hospital in Washington. He estimated that these abnormalities may be present in 5 to 15 percent of schizophrenics.

"Whether it is atrophy or failure of the brain to develop fully is not clear," Dr. Wyatt said. It does seem clear that the abnormalities exist long before the patient begins to hear voices or to drift away from normal emotional involvement with family, friends or the world.

The new evidence indicates that the disease is far more than a consequence of adverse familial, social and other environmental experiences as many American psychiatrists long believed.

Some scientists still maintain that these biological changes may be results rather than a cause of the disease.

But many biological psychiatrists today speak bitterly of the pain the earlier view inflicted on the families of schizophrenics: adding guilt to the agony of watching a spouse or child turn into an irrational, angry or apathetic stranger.

Nevertheless, few experts doubt that there are powerful social and environmental influences. The role of the family is seen as particularly important after a patient is released from a mental institution.

Many experts believe the chief task of brain scientists, in schizophrenia today is to discover just how environment interacts with heredity and the physical and chemical state of the patient's brain to evoke catastrophe.

Heredity appears to be a factor in the disease. Children who were adopted and reared apart from a schizophrenic mother or father are significantly more likely to become schizophrenic themselves than are the natural children of normal parents.

The new tools of molecular biology are being enlisted more and more in efforts to find the genes and gene products that express this heredity. But what those factors are and how they lead some individuals into the wasteland of mental illness is still a mystery.

Schizophrenia involves two different sorts of symptoms that seem to be linked to different features of the biology of the brain.

The hallucinations, the rages, the patient's belief that his mind is being controlled by an external force like radio waves or a television set are what scientists call the "positive" symptoms of the disorder. Laughter or tears may occur in totally inappropriate situations, and some rare cases involve violence or even the compulsion to kill on orders from an imagined higher power. It is these symptoms that are often ameliorated by the antipsychotic drugs and are thought to be most directly related to aberrent brain chemistry.

The negative symptoms are the indifference, the withdrawal from the world. It is these symptoms that often create the street people who quietly drag all their possessions along with them in bags and sleep on grates. Even with drug treatment, patients who show this array of negative symptoms are often on a grim downhill course from which they never recover.

WATCHING THE BRAIN AT WORK

Some of the most dramatic new observations of the schizophrenic brain in action have been made by a group at St. Elizabeths headed by Dr. Daniel R. Weinberger. They have watched the living brains of normal people and schizophrenics in the process of coping with mental tasks.

Using sophisticated electronic imaging equipment they have seen appropriate parts of the brain light up in a computer-generated image as increased chemical activity indicates heightened work by brain cells.

Schizophrenics and others were tested while they were performing a psychological test that measured their ability to correlate different kinds of data including colors, shapes and numbers. This exercise, the Wisconsin Card Sort test, is not particularly taxing for a normal adult, but has long been known to be extremely difficult for schizophrenics.

In a normal person, the image of a portion of the brain called the prefrontal cortex can been seen to light up as it reacts to this analytic task. In sharp contrast, the brains of schizophrenics remained quiescent as though they were unable to meet the physiological demands.

The experiment shows a physiological defect not just in schizophrenic brain, but in that brain's prothought processes.

Some brain scientists view this link to the prefrontal cortex as particularly interesting for several reasons. This brain area is important in cognition—the processes of thought and higher mental function that are so terribly disrupted in schizophrenia. Furthermore it is the last region of the brain to attain complete development and does this only in adolescence and early adulthood.

VIRUS SUSPECTED BY SOME

Perhaps significantly, the Wisconsin Card Sort is difficult for children, in whom the brain region is not yet mature. Schizophrenia rarely develops before the age of 15, which suggests that something may have interfered with development of the prefrontal cortex.

The nature and timing of the "something" are complete mysteries. Some scientists have suggested that a virus infection in a pregnant woman may set the stage for this outcome years later in her child, or perhaps a self distructive immune reaction or some toxin produces damage before birth or in early childhood.

One tantalizing clue that may be relevant to virus involvement is that significantly more people who become schizophrenics are born in late winter and early spring than in any other season. These evidently fateful months are known for the prevalence of many virus infections. But to date, solid evidence of damage by any specific virus or possible autoimmune problems in schizophrenia is lacking.

"My own sense is that there is some legitimate excitement in the viral and autoimmune areas," said Dr. Frederick K. Goodwin, the director of intramural research at the mental health institute. "But scientists of both those fields have to be respectful of the false starts made in the past."

Dr. Weinberger's group studied brain cell activity through a method that allowed them to gauge blood flow and cell metabolism in specific regions of the cerebral cortex, using inhaled xenon gas as an indicator. The method is only one of several developed recently that psychiatrists and brain scientists are using to study the disease-impaired living brain.

Many studies based on computed axial tomography, CAT scans, have shown structural abnormalities in the brains of some schizophrenics. Most notable were abnormally large ventricles, the hollow fluid-filled spaces within the brain.

That and related evidence indicates that some schizophrenics have somewhat less brain tissue than normal people do. Careful studies indicate that the findings are intrinsic to the disease, not just effects of treatment or hospitalization. The evidence also suggests strongly that whatever causes the enlarged ventricles does so before the first symptoms of schizophrenia appear and does not change, for better or worse, thereafter. Usually, by the time the patient first comes to the attention of a psychiatrist, the brain damage has already been done.

Some scientists hypothesize that these structural abnormalities are linked to the withdrawal and apathy classified as negative symptoms of schizophrenia.

The CAT scan evidence has led to a renaissance in studies of the schizophrenic brain, Dr. Weinberger said. Even more important results are expected from newer and more sophisticated brain imaging methods.

As a group, patients whose brains showed these physical abonormalities had poorer social adjustment before diagnosis. Later, they showed poorer response to drugs and to generally bleak outlook. But the findings were not sharp enough to be used in diagnosis of individual patients.

Such antipsychotic drugs as chlorpromazine have had profound impact on the treatment of schizophrenia and also on efforts to fathom the biochemistry of the disease. The drugs, a class called phenothiazines, interfer with the brain's production and use of an important brain chemical, dopamine. American scientists have used their understanding of those drugs to glean important clues concerning the involvement of aberrant brain chemistry in schizophrenia.

The evidence available today links the positive symptoms of schizophrenia with chemical rather than physical abnormalities, especally the brain's handling of dopamine, one of the chemicals that transmits signals in the brain.

That the phenothiazines interfere with the dopamine system suggested that perhaps excess dopamine was a factor in schizophrenia. The suspicion was strengthened by observing victims of Parkinson's disease, who lack sufficient dopamine activity. Parkinson's patients who take a dopamine promoter, L Dopa, to curb their shaking, halting movements and other physical symptoms also sometimes develop psychotic symptoms. Conversely, schizophrenics who are treated with drugs known to inhibit the dopamine system sometimes develop the stumbling gait and facial rigidity characteristic of Parkinsonism.

Other drugs, like amphetamine, that boost the normal brain's production of dopamine can produce symptoms like those of schizophrenia.

The resulting body of knowledge has produced the hypothesis that a key factor in schizophrenia is abnormal dopamine activity.

But the search for simple chemical solutions to the puzzle of schizophrenia has been frustratingly unsuccessful. Indeed, Dr. David Shore of the mental health institute likes to cite H. L. Mencken's idea that for any complex question there is almost always a simple answer—that is almost always wrong.

Scientists note that the true situation in schizophrenia may involve abnormality in the population of dopamine receptors on nerve cells in parts of the brain, possibly a shortage of a still-undiscovered dopamine inhibitor or some other possibility that has not yet occurred to anyone. The available evidence does not support any simple cause-and-effect link between the mental illness and excess dopamine. In fact studies show reduced dopamine in some brain tissues, leading some scientists to suspect there may be simultaneous excesses and deficiencies in different parts of the brain of the same patient.

While some form of the dopamine hypothesis may help explain the positive symptoms, specialists say, they do not yet seem to offer much enlightenment on the negative symptoms.

Furthermore, this baffling disorder is so far from uniform in its effects that many specialists prefer to call it a group of disorders rather than a single entity. One of the hopes of the new and highly sophisticated brain research, they say, is that the studies may help tease apart from the whole tangled skein some of the more homogeneous subgroups of the disease. This too could lead to important enlightenment and perhaps more effective medical intervention.

AUTOPSIES SUPPORT VIEW

Major recent autopsy studies have bolstered the view that enlarged brain ventricles are involved in schizophrenia, that parts of the cortex of the forward part of the brain appear thinner and short of the normal number of active nerve cells.

The evidence of malfunction of the prefrontal cortex seems powerful and offers researchers an important focus for future research.

Physical abnormalities in the brains of schizophrenicz were long denied by many American psychiatrists. Today the evidence is on a much more solid footing.

"We have made some good progress," said Dr. Samuel Keith, chief of the mental health institute's center for study of schizophrenia. "It hasn't been easy progress because the brain is a complex and inaccessible organ.

He described the new brain imaging techniques as exciting new windows on that inaccessible organ, offering important hope for the future of schizophrenia research.

"I think we are at a critical juncture today in terms of schizophrenia research," he said.

I Feel Like I Am Trapped Inside My Head, Banging Desperately Against Its Walls

(The following first-person account of the ordeal of schizophrenia was written by a woman who recently completed college despite repeated hospitalizations. Her identity is withheld to protect her privacy.)

Can I ever forget that I am schizophrenic? I am isolated and I am alone. I am never real. I play-act my life, touching and feeling only shadows. My heart and soul are touched, but the feelings remain locked away, festering inside me because they cannot find expression.

Can I ever forget that I am schizophrenic? Will I ever learn to live, to love unselfishly, to appropriate the beauties of life, to deny my hell and pain and darkness? Why is life like this? What have I done wrong? Have I created my own hell? If I did not create it, why was it inflicted upon me? What does it mean, all these weird feelings that shut me off from the rest of the world? Will they ever end?

Can I ever forget that I am schizophrenic? I am a ghost within myself, a spirit no one knows. Long ago when they locked us up forever, perhaps they were not so wrong. What good is physical freedom if the human feelings are trapped, unable to escape? I am in my own prison. I feel like I'm just stumbling around, grasping at straws hoping one will be the key to open my heart. It never comes, and I wonder if I'll ever give up.

It is hard to be schizophrenic. It means years of struggling and fighting to overcome a disease that defies submission. Many times I have felt that I was fighting my way up a dirt hill, and as I walked the ground crumbled beneath me, and I could make no movement. After nine years I can look back through a maze of pain and fear and see that I have moved and made progress: Many of the symptoms that crippled me for years have come under some control. The totally frustrating part of this illness is that it is always growing, always changing. There are always new symptoms, new fears to conquer. Sometimes I get tired, and it is the weariness more than the pain that brings tears to my eyes.

The most wearing aspects of schizophrenia is the fierce battle that goes on inside my head in which conflicts become irresolvable. I am so ambivalent that my mind can divide on a subject, and those two parts subdivide over and over until my mind feels like it is in pieces, and I am totally disorganized. At other times, I feel like I am trapped inside my head, banging against its walls, trying desperately to escape while my lips can utter only nonsense.

Some of the symptoms I experience now are different than when the illness first began but they are just as painful and just as powerful. At times my thinking about things around me becomes confused as is revealed by this entry in my journal:

I live in the shade and I try to capture its edge so I can contain it but it keeps growing. Then it's gone, but the sun is too hot, so hot it too becomes engulfed in shadows—sun shadows—the sots that bore through my head and make me spacey. There is no escape. The whole world is poison. I must hide.

Recently, my mind has played tricks on me, creating The People inside my head who sometimes come out to haunt me and torment me. They surround me in rooms, hide behind trees and under the snow outside. They taunt me and scream at me and devise plans to break my spirit. The voices come and go, but The People are always there, always real.

Life for most schizophrenics is a nightmare full of fears and doubts about oneself and about reality; they have a distorted view of that most profound question of how they relate to the world around them. Boundaries become unclear and other people are frightening and not to be trusted. Thus, the very thing which could bring relief—closeness to other people—is shunned as something horrible and dangerous. For this reason it is absolutely essential to have someone to depend on, to draw the schizophrenic out of his jungle of terrors and eventually more into the less frightening world of reality.

One of the hardest issues for me to deal with has been trust. My mind has created so many reasons to fear the real world and the people in it that trusting a new person or moving to a new level of trust with a familiar person presents a terrifying conflict that must be hammered out over and over until I can find a way to overcome my fears or in a few cases give up the battle, even if just for the time being. The intensity of this conflict makes it hard to build relationships. It's hard for the family to help. It's difficult for them to understand the nature of the disease.

Therapy with schizophrenics can go on for years before a level of trust is built up sufficiently for the patient to use his therapist as a bridge between the two worlds he is confronted with. For me, each new experience of trust adds a new dimension to my life and brings me that much closer to living in reality.

Living day to day is a challenge because it is just simply *hard* for schizophrenics to live in a world that is so troublesome to them. My fears are so intense that before I do most things I must pass through a "wall of terror" that stands between myself and my goal. Leaving the house, talking to someone, or taking a walk can create panic, simply because I do not feel like part of the world. It is a foreign place to me. Since my childhood I have felt like an outsider looking in.

Schizophrenia is not just an illness, it is a way of life, and it is a life constantly disrupted by symptoms. I have dealt with a totally delusional world in which I was God—The Creator and The Sufferer—and the trees held magical power while a great wall and glass dome cut me off from the rest of humanity. More recently, I have gone through excruciating periods of thought-interference and feeling that I did not exist, experiencing my body as a machine that I could see and feel but which I could not perceive as being in the world. The most frightening part for me is how quickly I can be taken as if by a force and projected into another "state" in which all my perceptions are altered and the world becomes a bizarre place. Sometimes there is confusion about which is the true reality—the objective world or the psychotic world:

Today I saw reality, felt it, lived in it for a while. It was exactly as though someone had thrown a switch and turned a black and white TV into color—like the Wizard of Oz. It was incredibly beautiful and extremely intense. I felt every color, heard every light, saw the world as everyone else sees it—as a vibrant, pulsating complex of what life is all about. I heard in my head very distinctly, "I am both The Creator and The Sufferer."

My mind is often tortured by the movement back and forth between two worlds, neither of which I clearly understand. The only real peace or sense of "feeling good" comes with the relief of these symptoms, even if just for a short time. In my experience, the best source of relief is other people who are sensitive enough to understand me and patient enough to help me through my times of unreality. I have done much work but I still seek reassurance that the real world is not as hostile as I had imagined and that I do indeed have a place in it. Perhaps acceptance in the real world can give me the strength to sever those painful ties to the world of my imagination that have for so long held me captive.

AID IN DAY-TO-DAY LIFE SEEN AS HOPE FOR SCHIZOPHRENICS

(By Daniel Goleman)

Innovative programs scattered around the country are now offering the first rays of hope in decades for millions of tormented victims of schizophrenia, which has become the nation's worst mental health problem.

"We've learned that if we have the will to provide decent care for schizophrenics, their condition could be sharply improved," said John Talbott, a former president of the American Psychiatric Association.

But other experts say the growing ability to cope with schizophrenia is not being matched by a broad, coordinated effort to apply it. That failure, they say, is enormously costly to the nation both in the money spent for excessive hospitalization and in the shattered, unrepaired lives that result.

Schizophrenia's victims can be completely disabled by unsettling delusions or an inability to think clearly; they may find themselves shouting back wildly at imaginary voices or sinking, emotionless, into deep apathy.

Most of the new approaches in treating the baffling disorder focus on practical help for patients and their families in managing everyday problems: diminishing the stress that sets off some of the most disruptive and painful behavior, as well as teaching skills needed to achieve friendships, jobs and success in negotiating a bureaucracy to obtain the government benefits that any sick or poor person is entitled to.

"The environment in which the person lives has become the key factor in treating schizophrenia," said Dr. Samuel J. Keith, who heads the schizophrenia branch of the National Institute of Mental Health.

The trend reflects the inability of scientists thus far to discover the root causes of the disorder as well as the failure of powerful drugs to ameliorate some of the most prevalent symptoms.

But the innovative approaches to the handling of schizophrenia are demonstrating dramatic improvements in patients' return to mental stability.

A recently completed 30-year study of hospitalized schizophrenics who had been given up as hopeless, but then were released in a program that closely manages and monitors their lives, has found that two-thirds of them are now living normal lives in the community, half of them without any signs of the disorder.

There are a range of treatments that, taken together, offer new hope:

Family management, the fastest growing of the new approaches, encourages the patient's family to keep stresses in the home minimal and teaches family members how to handle the day-to-day difficulties of living with a schizophrenic.

A full spectrum of community services—ranging from hiring neighbors to help look after schizophrenics to 24-hour crisis teams whose members will move in for days at a time with a schizophrenic in crisis—has proven capable of keeping all but a small minority of schizophrenics out of psychiatric hospitals while speeding their improvement. And when schizophrenics are helped to get the government funds due them, they need not live in shelters or on the streets.

Havens of several sorts offer new kinds of protected environments in which schizophrenics can rebuild their lives. In New York City, Fountain House finds sheltered jobs and apartments for schizophrenics leaving hospitals. In Boulder, Colo., a program sets up patients in households with two members of a treatment team.

PROMISE COMES AMID RESEARCH OPTIMISM

The promise of the new family and community programs is strengthened by recent research findings that portray a far more positive long-term prognosis for many schizophrenics than is commonly assumed, even by many of those who treat them.

Next month, for example, in an article in The Archives of General Psychiatry, a team of researchers at the University of Pittsburgh will publish results of a study showing that teaching the families of schizophrenics how to care for them can drastically improve the course of the illness.

It is not yet clear whether the new programs might not prove too expensive or unwieldy in some urban settings where social services, under the best of circumstances, are often mired in bureaucracy.

Some schizophrenics continue to be treated individually by psychotherapists, usually in combination with drugs, and with varying degrees of success. While there are some promising developments in psychotherapy, for the vast majority of schizophrenics the hope lies in the new approaches.

One of the factors behind it is a radical new understanding of schizophrenia itself: that the disorder goes far deeper than had been thought and that recovery does not end when the more obvious symptoms—the delusions and hallucinations—stop.

Effective treatment, it is now thought, requires an ongoing, dogged effort to help a person overcome the apathy and other problems created by the longlasting emotional and other deficits, and to rebuild crumbled social relationships.

One of the more inventive methods used, called "network therapy," constructs a support system for former hospital patients who otherwise would be isolated and alone.

"These are people who have been in and out of the hospital for the last 10 years and whose natural network of family and friends has gradually eroded," said Paul Wagner, a clinical social worker who directs the Mount Tom Institute in Holyoke, Mass., one of several agencies that provides such services.

"Network therapy begins with a series of meetings to which you invite absolutely everyone who knows the person and might help him," he said. "It might be a distant relative, some old friends, the grocer, maybe some neighbors. Everyone meets and you tell them the person's whole story. These stories are very tragic, very moving. By the end, just about everyone wants to help somehow.

"Each person does a small part," Mr. Wagner added. "One neighbor says he'll call more often, someone else volunteers to bring him to church. When you put it together, you have a treatment plan. Since we began network therapy in 1982, not a single person in the program has been readmitted to the hospital."

An important factor in this success, according to Mr. Wagner, is a crisis team available 24 hours a day. It not only makes house calls to help resolve crises, but also has access to families in the area who keep an extra bedroom available for the emergency team, where a person in crisis can stay and be treated for up to a month.

There is great interest among professionals in teaching families better ways to care for schizophrenic members, at least until they can live on their own. "There's hardly a place in the country where, in the last three years, they have not begun to use some form of family management," said Dr. Talbott. "It is an idea whose time has come."

Carol Anderson, a psychologist at the University of Pittsburgh who is one of the primary developers of the family management approach, said: "We emphasize that schizophrenia seems to be due to a biological vulnerability that is triggered by stress. Most families have some private theory about what caused it, often one that makes them feel guilty, like their child falling out of bed. They're relieved to learn that no one single life event causes schizophrenia."

GUIDES TO CREATING A HELPFUL ENVIRONMENT

The training, which Dr. Anderson describes in detail in "Schizophrenia in the Family" (Guilford Press), typically begins with a one-day session for families in which a member is being treated for schizophrenia. Families are told that because schizophrenics are easily overstimulated and distracted, they should avoid extremes of conflict and criticism on the one hand, or extreme enthusiasm on the other. They are also advised to create an attitude of "benign indifference" toward many of the symptoms of schizophrenia.

But families are also urged to set reasonable rules for the patient, so as "not to confuse the need for low stimulation with permissiveness." Even the most stable of families would be hard-pressed to deal with a member's insistence that the television screen [illegible] covered with aluminum foil to thwart eavesdropping.

Families are also urged to let patients withdraw for a time when they need to do so, for example, taking meals alone or staying in their rooms when company comes. At the same time it is crucial that burdened family members maintain friends and sources of pleasure outside the home.

Research done by Dr. Anderson shows a one-year relapse rate under 10 percent in patients treated using family management. For patients who receive only drug treatment the relapse rate was 50 percent. According to the researchers, similar patients who receive no treatment at all have a relapse rate of 60 to 80 percent in the first year after leaving the hospital.

"The main rationale for family management is to calm the emotional climate and offer the family support, not point fingers or try to change the family dynamics," said Christine McGill, a social worker. She is training the staffs of hospitals engaged in a major five-year, $5 million study of family management being conducted by the National Institute of Mental Health. The study, now in its first year, is under way at four hospitals, including the Payne-Whitney Clinic in New York City and the Long Island Jewish-Hillside Medical Center in Glen Oaks.

A major goal of that study is to determine the extent to which dosages of the drugs used to treat schizophrenics can be lowered as families become more adept at handling the patient. The drugs, called neuropleptics, can have serious side effects, such as loss of muscular coordination. The standard treatment is to maintain patients with chronic symptoms on the drugs for years, but many experts now believe that family management and similar support can allow symptoms of schizophrenia to be controlled with intermittent or much lower doses of the drugs, or even no drugs at all.

With the proliferation of family management, Dr. McGill cautions, often what is offered to families is simply a one-day training program. "They neglect the crucial part the contact with families to help them through the large and small crises," she said. "You need to make a minimum two-year commitment to help a family after a member has had a schizophrenic episode."

PROGRAMS FOR THOSE OUTSIDE THE FAMILY

While the goal of family management is to help the person, finally, to become independent, not every family is willing or able to put up with the difficulties that having a schizophrenic at home entails. And, of course, many patients have no families to take them in. For such people other programs have evolved with principles and methods similar to family management.

One of the most innovative is a treatment arrangement that, in effect, creates a family for a schizophrenic while he is in treatment. This program, operated by Maitri Psychological Services of Boulder, Colo., creates a household in a rented apartment or house with a schizophrenic patient and two roommates, who are trained as part of an eight-member treatment team. Members of the team are with the patient as needed day and night.

Although each patient in the program is in psychotherapy three times a week, the emphasis is on the healing value of ordinary daily activities in the household.

"Our experience is that when highly disturbed people are in the intensive company of healthy people, they tend to become healthier," said Edward Podvoll, the psychiatrist who directs Maitri.

One of the main deficit symptoms of schizophrenia is a wildly wandering attention. The Maitri treatment puts a special emphasis on the quality of attention that patient and companion bring to what they do.

"It is all done from the point of view of helping the patient engage in a mindful way in every activity, to help them recover their attention and concentration abilities."

Maitri and other private programs like it, however, are available only to a limited number of patients, and cost about as much as one of the better psychiatric hospitals. Maitri, for instance, ranges from $6,375 to $9,850 a month, and although some health insurance plans will pay for it, few patients or their families can afford such expense on their own.

For the several hundred thousand schizophrenics across the country who need continuing treatment, there is a longstanding Federal plan for a spectrum of community services. The plan, dating back to the 1970's, was to be a replacement for the "warehousing" of chronic patients in large state hospitals. But few states, it is now widely acknowledged, allotted sufficient funds for the community program.

One notable exception is a highly successful program that began as an experiment in Madison, Wis.

"We started by moving a large group of patients out of the state hospital into town, and moved the staff right along with them" into the community, said Leonard Stein, the psychiatrist who directed the project. "When we evaluated the needs of each patient we found that they had been coming back to the hospital because, for example, they got into trouble with a landlord and were evicted, or they didn't know how to get their social security benefits and got very upset."

Compared to patients who were treated in the hospital as a part of the usual follow-up treatment, the patients in this program had one-tenth the rate of relapse, had far fewer symptoms of schizophrenia, and were generally more satisfied with their lives. Moreover, the cost per patient in the community program was about $15,000 a year, while a full year in the hospital would cost $70,000.

Despite the success of the Wisconsin experiment, very few states have allocated the funds that would set up similar programs. One of the rare exceptions is a community-based program in western Massachusetts, created as the result of a legal action taken in behalf of patients at the state hospital in Northampton. In 1972 the hospital had 1,400 patients; now it has just over 200, a very small number for a region with 800,000 residents.

The network therapy at the Mount Tom Institute is part of the Massachusetts program. Among the other unusual services offered there is "respite care," where a family who is caring for a schizophrenic member can, when a particularly difficult crisis occurs, have the patient stay in a supervised house for a few days, or have a mental health worker come and stay with the family to help them out. In addition, specially trained families are available who will take in schizophrenic patients from other families for anywhere from a week to two months.

Such services are part of a concerted effort to keep patients living in the community, even when they are having psychotic episodes. "The state hospital is the last resort, not the first resort," said Steven J. Schwartz, the lawyer whose suit created the system.

The key to the Massachusetts program is case management, the assignment of around 30 patients to a service coordinator whose task it is to see that they get whatever help they need. This means, for example, that if someone is too confused or apathetic to find an apartment, the service coordinator will do it with him, and help him move in. And if an ex-patient needs looking after in his apartment, the service coordinator might hire neighbors to keep an eye on him.

There are public funds already allotted to which schizophrenics are entitled, but are often too confused or naive to get on their own. "To get the money, you're got to know exactly which funds you've entitled to, where to apply, how to answer the question," said Mr. Wagner. "One of the main jobs of the service coordinators is to go along with their clients to all these places and help them through each step."

The potential sources include insurance plans and veterans' benefits, Medicare and Medicaid, and Social Security for the mentally disabled. In addition, in Holyoke there are funds available to help pay for heating oil, a food bank that provides the proverty-stricken with groceries until they can get food stamps or other funds, and a program that pays the security deposit on an apartment—often one of the crushing financial obstacles for those who have been existing on the streets.

NEW YORK PROGRAM IS OFTEN COPIED

Finding a group of friends and a job is seen by many memtal health experts as key steps for those who have suffered from schizophrenia for many years. The most copied program that focuses on these needs is Fountain House in New York City.

"We start with the assumption that schizophrenia is a condition that isolates people and destroys their confidence," said Jim Schmidt, the director. "We give them a place to go where they are welcomed, even celebrated. They are not here to be treated or trained; it's a clubhouse."

Dozens of businesses have entry-level jobs reserved for Fountain House. Members try these jobs part-time, at first accompanied by someone from the staff who will do the job if the member fails at it. If the member succeeds, in six months he moves on to another job, until he is finally able to get a full-time job on his own.

There are now nearly 200 programs nationwide based on the Fountain House approach to getting former patients employed again. But while many communities have one or another part of the services offered in western Massachusetts or by Fountain House, programs with the entire range are few and far between.

"People are only just becoming aware that community treatment can be successful, if done right," Dr. Stein said. "There is no real alternative to a community program; the old hospitals are enormously expensive. And this works."●

● **Mr. MATTINGLY.** Mr. President, when the U.S. Commerce Department released its trade deficit figures for 1985 those figures clearly indicated that the U.S. trade deficit had continued its unchecked growth for yet another year. Of even greater concern is our trade imbalance with Japan which soared to a record level of almost $50 billion, nearly one third of this country's total trade deficit.

I was encouraged last year when the President announced that the administration would self-initiate a number of section 301 trade investigations into certain unfair Japanese trade practices. While success has been reported in negotiations concerning leather and pharmaceutical products, little progress has been made in eliminating Japanese barriers to imported cigarettes. U.S. Trade Representative Clayton Yeutter has written to me to

THURSDAY, MAY 1, 1986.

NIADD

WITNESSES

GENEVA L. MOSS, BOARD MEMBER, ASTHMA AND ALLERGY FOUNDATION OF AMERICA

HENRY MOSS

JAMES N. APPLEBAUM, DIRECTOR, COMMUNICATIONS AND PUBLIC AFFAIRS

Mr. NATCHER. Our next group of witnesses will be, Mrs. Geneva Moss, Mr. Applebaum.

Mrs. Moss, how shall we proceed? We are delighted to have you before the committee, and we will be pleased to hear from you.

Mrs. GENEVA MOSS. Thank you, Mr. Chairman, subcommittee members. Good afternoon, my name is Geneva Moss. I am from Rockfield, Kentucky, and a registered nurse at Greenview Hospital in Bowling Green.

I am accompanied by Mr. Jim Applebaum, Director of the Communications and Public Affairs Committee, and my husband Henry.

I am speaking to you this afternoon as a member of the National Board of Directors of the Asthma and Allergy Foundation of America.

AAFA is a national voluntary health agency dedicated to serving the estimated 40,000,000 children and adults who are victims of these widespread illnesses.

I can tell you, from my personal observations as a health care progressional, that asthma and allergic diseases are very, very significant health problems worthy of our Nation's best scientific and health care minds and energy.

In our Second Congressional District in Kentucky alone, AAFA estimates that about 85,000 citizens suffer from one or a combination of these diseases.

Asthma and Allergies used to be popularly thought of as either minor nuisances, short-term illnesses that could be usually controlled just by taking over-the-counter medications, or illnesses brought on by emotional problems. We now know for certain that these are myths.

Since the early 1970s, a truly amazing blossoming of scientific knowledge about the immune system has begun to allow physicians and patients to gain a much fuller understanding of the causes and the treatments that can be applied to control many forms of asthma and allergic diseases.

In our Community Hospital in Bowling Green, it has been only in the past few years that we have had on staff a specialist in asthma and allergy medicine, a sign I believe that this health problem is widespread and worthy of quality professional attention.

The engine of the amazing growth in knowledge about the immune system and immunologic diseases, including asthma and allergies, has been the Federal Government's investment in the work done at and sponsored by NIH, particularly the National Institute of Allergy and Infectious Diseases, and the National Heart, Lung and Blood Institute.

This House Appropriations Subcommittee has repeatedly acted on a vision that has supported the work of NIAID and NHLBI, providing both the seedcorn and the growing conditions that make for a healthy and hearty crop.

In fact, your foresight has enabled the combination of various scientific specialties to come together, in NIAID's Regional Centers Program and in NHLBI's SCORs, to produce some truly outstanding basic research and clinical advances in the diagnosis and treatment of asthma and allergic diseases.

Today, though, we are very concerned and alarmed that the impressive fertilization and growth conditions that have been previously established may be allowed to lie untended, due to the accountant's sharp pencil in response to the Gramm-Rudman-Hollings Balanced Budget requirements.

We believe that it is unfair and very unwise to seek a balanced budget by erasing the health needs of 40,000,000 American children and adults.

We have a lot of work ahead of us, now that good science is on our side, before we can announce any sort of victory over asthma and allergic diseases.

Right now, deaths due to asthma are on the rise, after a long and steady decline that appears to have hit bottom in 1977. Scientists are not sure—with more knowledge and much better medications—why this is happening.

Yet, they all point to the absolute benefits of better patient education about this disease, in order to control it and prevent life-threatening situations.

Asthma continues to be a leading cause of school days lost.

Allergic rhinitis, often called hay fever, is a big threat to productivity at work and at school.

50 or so Americans die each year from severe allergic reactions to insect stings. Others are at risk.

Many hospitalized patients suffer allergic reactions to medications that are meant to help them.

We have a great deal to learn about food allergies, and about the more general area known as adverse reactions to food.

We are just at the dawning of an appreciation of the number of workers who may be victims of asthma and allergies to chemicals and other substances where they work.

We are just now finding out about the threat to some people with asthma from a classification of preservatives used in some foods: Metabisulphites.

As we become more physically active, we are also seeing more reported cases of exercise-induced asthma. We already know that a significant percentage of people with asthma, as well as those with allergies, are susceptible. We need surer controls.

The promotion of unproven techniques and remedies to asthmatic and allergic Americans has shot up like a weed compared with our ability to check these unfounded claims.

Last year, AAFA estimated the cost to Americans by those asserting the value of unproven techniques at between $500,000,000 and $1,000,000,000. Some of this country's most popular new health books make claims that are hair-raising to responsible health care providers.

Combating quackery and questionable treatment and remedies is a difficult process under the best of circumstances. It is nearly impossible when research is curtailed or eliminated by the whack of the accountant's cost-benefit hatchet.

Mr. Natcher, committee members, we who volunteer our time and energy on behalf of our children, neighbors and friends with asthma and allergic diseases know that we have only recently come from the shadows.

The momentum of science is finally on our side. We believe that the President's proposed budget for NIAID and NHLBI, cutting very significantly research grants, research training and interdisciplinary research and clinical center programs is a cut against the grain.

We ask you to augment, not subtract from government's support for the hopes of one of every six Americans.

Mr. Applebaum will now provide you with our specific requests.

[The statement of Mrs. Moss follows:]

ASTHMA & ALLERGY FOUNDATION OF AMERICA

Dedicated To Helping People Today And A Brighter Tomorrow Through Research Immunology

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Testimony Before

THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

Regarding

FISCAL YEAR 1987 APPROPRIATION FOR
THE NATIONAL INSTITUTES OF HEALTH

List of Witnesses

GENEVA MOSS, R.N.
Member of the National Board of Directors
Asthma & Allergy Foundation of America

Accompanied by

John B. Wynne, Esq., National President
Asthma & Allergy Foundation of America

David J. Branson, Esq., Vice President, Public Policy
Asthma & Allergy Foundation of America

May 1, 1986

Mr. Chairman, my name is Geneva Moss. I am a member of the National Board of Directors of the Asthma & Allergy Foundation of America (AAFA). Our Foundation is a national voluntary health agency dedicated to serving the estimated 40 million victims of asthma and allergic diseases. I am from Rockfield, Kentucky, and a registered nurse at Greenview Hospital, in Bowling Green. A rural region, nevertheless our community hospital now has on staff a specialist in asthma and allergy medicine, an indication that these diseases are being recognized, diagnosed, and treated in greater numbers than ever before. I also know from firsthand observation that a significant number of patients with asthma and other respiratory diseases are entering our hospital for care.

In our 2nd Congressional District alone, Mr. Chairman, we estimate that 85,000 children and adults are victims of these very common diseases. They are enormously costly. They are major robbers of schooling and workdays. We are also very alarmed and recent published reports indicate that deaths due to asthma, after years of decline, have been steadily rising since 1979. They are rising despite better trained health care providers, and despite more effective medications that are now available.

We also know, Mr. Chairman, that the incidence of serious asthmatic and allergic illness, as well as deaths due to asthma, are over two times higher among children in medically-underserved areas than among the population-at-large.

Mission Statement

The Asthma & Allergy Foundation of America (AAFA) is the national focus in the voluntary sector for the needs of the many millions who must continue to search for choices that will bring them better health and a reduction in the staggering costs due to these illnesses. Our liaison with patients and their families, with health care providers and health educators across the nation, clearly show that the magnitude of this public health problem continues to be great.

Magnitude of the Problem of Asthma and Allergic Diseases

Until the 1970's, when the science of immunology and the study of asthma and allergic diseases began to take its place within the mainstream of American scientific progress, knowledge about the true nature of asthma and allergic diseases was clouded. We all knew people with these illnesses, but misconceptions and myth downplayed their physical,emotional, and economic costs. Only in the late 1970's, when the Federal government convened a scholarly task force to examine the true magnitude of these illnesses did we first come to really undderstand the true nature of the problem and the challenges facing us:

- One of every six of us are victims of these diseases;
- Nine million Americans suffer from asthma, approximately one-third of whom are children.
- An estimated 4-5 thousand Americans die per year from severe asthma attacks. this despite widespread knowledge of life-saving techniques, effective medications, and methods to prevent such terminal conditions.

- Asthma is a leading cause of lost schooldays in our country.

- Extreme allergic reactions to insect stings claim the lives of 50-75 Americans each year.

- Allergic rhinitis, commonly known as hay fever, is the cause of at least 130 million lost school and work days per year.

- Confusion among the public about the causes and proven methods of diagnosing and treating asthma and allergic diseases has provided very fertile ground for the purveyors of unproven methods, today estimated by AAFA to cost Americans between $500 million and $1 billion each year. Highlights of Advances Effecting Asthma and Allergic Diseases

As the most prevalent of all immune system diseases, scientific investigation of the physiological and biological aspects of asthma and allergic diseases have been critical to our growth in understanding of other immune system disorders. Through growing scientific sophistication and the introduction of immunopharmacologic and biochemistry to the mix of disciplines applied to the study of these diseases, we have moved past the only partially effective treatment of end-stage symptoms, such as inflamation cause by the release of histamines, to an appreciation of the potential for switching off the entire allergic process via pharmacological manipulation.

Work now already begun and planned are taking us into areas that truly promise major future clinical advances, such as:

- Understanding the relationships between the immune system and the endocrine and central nervous system;

- Chemical detailing of neurotransmitters, agents that carry nerve impulses which prompt bronchial hyperirritability and mucus secretion;

- Differentiating lung and skin conditions from toxic and irritating effects of chemical exposures versus those of a truly allergic nature, a cause of significant occupational problems in some industries.

- A multi year study of the effects of immunotherapy (allergy shots) on victims of allergies to ragwood and house dust mites.

The experts inform us that science promises great advances toward controlling--virtually curing--many forms of asthma and allergic diseases by the end of this century. Yet, Mr. Chairman, we believe that the promise, for the 13 year old boy in West Virginia who still must be frequently hospitalized with severe asthma attacks, for the retired widow in Massachusetts frantic for the financial means to seek specialized care and almost unable to speak for her labored breathing, for the disadvantaged urban child whose devastating allergic asthma remains unmanageable, will vanish or be long postponed unless we maintain and increase public support for:

Basic research, our only hope for effective control of these diseases;

Interdisciplinary research and effective clinical applications, involving the much needed cross-fertilizing of specialties and laboratory and patient approaches to relate different areas of knowledge; and

Outreach, focused on developing, testing, and offering patients and their families effective education and valid facts in order to understand and cope with the illnesses.

Sadly, Mr. Chairman, from all we now read and hear about reductions mandated across the board by Gramm-Rudman-Hollings, all of these areas may be plucked and punished. It is a bad deal for the future of our people--one of every six of us!

We are aware and greatly appreciate this committee's long-standing support for public investment in the science that is undertaken at the National Institutes of Health and, within NIH, research into asthma and allergic diseases conducted by the National Institute of Allergy and Infectious Diseases, and the National Heart Lung and Blood Institute. Your support of NIH and our mission have a strong kinship.

However, we believe that the President's FY 1987 budget request for NIAID and NHLBI casts a long shadow over the prospects we have sofar labored hard to create and preserve. More specifically:

- In FY 1987, the President's budget would support only 421 competing research project grants. For both noncompeting and competing grant awards, this would mean a 13 percent reduction from full funding requirements. We believe strongly that this will have very serious consequences on basic research in allergic and immunologic diseases.

- If the President's budget is left as is, NIAID would be able to support just 375 research trainees, compared with 518 trainees in FY 1985. The decline would have the most negative effect throughout the field of biomedical research. New advances that hold all the promise of potential controls or cures for the victims of asthma and allergic diseases would dwindle severely.

- The very remarkable NIAID research centers, where the various disciplines are combined and laboratory and clinical work goes on hand-in-hand, would shrink and perhaps start to wither away. The number of centers would diminish to 14 from 18. Only noncompeting centers would be funded. And the average award to a center would be reduced by 30%.

This is not a very rosy picture, Mr. Chairman. It is not even one which will come close to preserving the status quo. In fact, it is bleak. What's more, what also disappears as a result of the President's budget for

NIAID is the outreach, the education and understanding that directly empowers the patient and the public to choose better health behavior.

Mr. Chairman, AAFA recognizes the urgency of government-supported medical-scientific research to develop treatments and cures for the epidemic of acquired immunedeficiency syndrome (AIDS). The threat is significant and should be dealt with forcefully and directly. Even so, we believe that appopriations for research into AIDS should not jeapardize the momentum achieved in recent years in asthma and allergic diseases research.

The prospects for work by the NHLBI in asthma is equally handicapped by the President's budget, we believe. Like that of NIAID, NHLBI would be unable to maintain the very important balance between research projects, research centers, and research and development contracts. Particularly, we note that the President's budget request would reduce support for NHLBI's SCORs from 11.7% to 10.9 % of total extramural funding. We are also alarmed that the Institute's R&D contracts, under the proposed budget would account for just 7.5 per cent of total extramural funding, for long maintained at or above 10% of total.

Specific Recommendations

I. For the National Institute of Allergy and Infectious Diseases

- Fully fund all noncompeting research project grants.
- Fully fund competing research project grants to the level of 50% of approved grants
- Fully fund 18 ongoing centers, permitting the addition of one new asthma and allergic disease center, and an outreach demonstration component to each CIRID.

- Increase funding for other research grants, to support 120 research career awards, strengthen medical school faculties in requisite basic and clinical studies on the immune system,and increase support for minority biomedical grants.

- Increase funding to permit the support of 600 full time training positions, enablinb the future cadre of investigators to provide continuing and new ideas and approaches to the diagnosis, treatment and prevention of allergic diseases.

- Increase funding for research and development contracts to maintain ongoing efforts in allergic and immunologic diseases.

- Increase funding for the intramural research program to maintain ongoing efforts and begin activities, specifically to perform a clinical study of the value of immunotherapy in treating food allergies, study the growth of human mast cells in culture and prepare monoclonal antibodies against such cells, study various treatments, including nasal steroids and antimetabolites, for nasal polyps; and study the underlying mechanisms of urticaria and angioedema.

- Increase funding support for research management, providing for an increase in the number of FTE's to effectively manage and administer outreach programs in asthma and allergic diseases.

II. For the National Heart, Lung and Blood Institute

- Provide funding of $93 million to adequately support SCORS, including 21 specializing in lung diseases.

- Increase funding support for research and development contracts, to allow new trials to begin in FY 87

- Provide funding for the intramural research program to the extent needed to maintain current effort and overcome inflationary erosion.

Mr. Chairman, the central role that has been played by NIH in the strides our nation has already made against asthma and allergic diseases has had a dynamic and highly favorable impact on health care that is today available to America's 40 million victims of asthma and allergic diseases. We believe that, with your continued insistance, this country can reduce health care costs dramatically, and alleviate a tremendous amount of unfortuante and unnecessary death, pain and suffering in all regions of our land.

Thank you.

Mr. **Applebaum**. The Asthma and Allergy Foundation of America urges this committee to bolster the work of the National Institute of Allergy and Infectious Diseases by fully funding all noncompeting research project grants.

Fully funding competing research project grants at the level of 50 percent of approved grants.

Fully funding the 18 ongoing Regional Research Centers, permitting the addition of one new Asthma and Allergic Disease Center, and an outreach demonstration component at each of the Centers for Interdisciplinary Research in Immunologic Diseases.

Increase funding for other research grants, in order to support 120 research career awards and strengthen medical school faculties in the basic and clinical specialties needed to further our national knowledge about the immune system, including minority biomedical grants.

Increase funding for R&D contracts in order to maintain ongoing efforts in allergic and immunologic diseases.

Increase funding for the intramural research program so as to specifically perform the following: A clinical study of the value of immunotherapy in treating food allergies; a study of the growth of human mast cells in culture, and preparation of monoclonal antibodies against these cells; a study of various treatments for nasal polyps; and a study of the underlying mechanisms of urticaria and angioedema.

Increase funding for research management, enabling NIAID to increase the number of full-time equivalent personnel to manage and administer outreach programs in asthma and allergic diseases.

Also, to provide the level of support required by the National Heart, Lung and Blood Institute to further work aimed at combating asthma, we recommend:

Funding of $93,000,000 to support the SCORs program, which includes 21 centers specializing in lung diseases.

Increase funding for R&D contracts, to allow new trials to begin in fiscal year 1987; and funding NHLBI's intramural research program to the extent needed to maintain the current effort and overcome erosion due to inflation.

Mr. Chairman, we know this subcommittee well appreciates the central role that has been played by NIH in our progress so far against asthma and allergic diseases.

Through your continued insistence on this well-placed use of public funds, we are confident that this country can reduce health care costs, alleviate a great deal of suffering and unnecessary death, and increase educational, employment and leisure choices of many millions of Americans.

Thank you.

Mr. NATCHER. Thank you very much, Mr. Applebaum, you gave us a good statement. Thank you very much.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESSES

BONNIE STRICKLAND, PROFESSOR OF PSYCHOLOGY, UNIVERSITY OF MASSACHUSETTS, AMERICAN PSYCHOLOGICAL ASSOCIATION

ALAN KRAUT, ASSOCIATE EXECUTIVE DIRECTOR, AMERICAN PSYCHOLOGICAL ASSOCIATION

Mr. NATCHER. Our next witness is Dr. Bonnie Strickland.

Mr. Conte, I yield to you at this time.

Mr. CONTE. I want to extend to Bonnie Strickland my own warm welcome. Dr. Strickland is a clinical psychologist and Professor of Psychology at the University of Massachusetts in Amherst. Bonnie recently became the 95th President of the American Psychological Association, and Dr. Strickland is a strong and dedicated leader in her field, and she has used her energies well. You have helped to move this field forward in a very progressive way, Bonnie, and we are proud to have you here today.

Mr. NATCHER. Dr. Strickland, it is a pleasure to have you before the committee.

Ms. STRICKLAND. This is Dr. Alan Kraut, Associate Executive Director, American Psychological Association.

Mr. NATCHER. We are delighted to have both of you.

Ms. STRICKLAND. I am pleased to testify today on behalf of APA's 87,000 members on the subject of Alcohol, Drug Abuse, and Mental Health appropriations.

I also want to point out that the levels of funding recommended by APA are supported by a coalition of over 40 mental health professional organizations, consumer groups, and others.

I would like to summarize my testimony and focus on our concerns at the National Institute of Mental Health. I ask that the whole of my testimony be included in the record as if read.

APA and the mental health coalition urge the committee to fund NIMH research at $272,000,000. This level would allow NIMH to fund 425 new research grants. In contrast, the President's proposal would support only 257 new grants.

The Administration's low grant number is part of a new grant "stabilization" policy. Its net effect is to lower the base line number of grants for consideration for years to come. This policy flies in the face of Congress' recent efforts to increase NIMH research support, and we urge the committee to reject it.

In the area of NIMH research training, APA and the coalition urge Congress to appropriate $26,600,000. The number of trainees supported by NIMH has declined drastically in recent years. Our proposal would help reverse this trend.

A second and related training concern of ours is the need to increase behavioral science research training at the pre-doctoral level. A 1985 Institute of Medicine report recommended such an increase, and Congress has endorsed the recommendation in its appropriations report for two years now, without response from ADAMHA.

In fact, ADAMHA recently proposed a policy for research training that is likely to reduce support at the pre-doctoral level even further. Again this year, we ask the committee to direct ADAMHA and NIMH to design a policy to implement the recommendations of the Institute of Medicine and Congress.

I would like to also address the NIMH Clinical Training Program, a program with which I am personally very familiar. APA and the coalition support funding this program at $26,000,000.

Because of past reductions in support of clinical training, Congress has focused the program to provide training for mental health professionals only to work in shortage areas; that is, among such populations as the elderly, children, minorities, the chronically mentally disabled, those in rural areas, and in our Nation's jails.

The clinical training program has the capacity to respond directly to these needs by requiring students to "pay back" the Federal Government by working one year in a designated shortage area for each year of Federal support.

APA has asked Congress to mandate that as much as 75 percent of all clinical training funds awarded to each profession be obligated with a payback requirement. At present, more than 50 percent of the funds awarded to psychology, nursing and social work carry the payback obligation. Only 7 percent of psychiatry funds do.

Last year, in report language, the Senate Committee indicated its interest in mandating greater use of the payback requirement and directed NIMH to provide a detailed report on its use, and on the use of non-payback; that is, institutional, support.

ADAMHA recently provided the committee with its report, and we believe the report further substantiates the need for mandating payback. The report makes clear that when support goes for non-payback activities, the relationship between the use of the funds and the programs goals becomes clouded.

The report notes, for example, that in the case of psychiatry, funds are used to train general medical practitioners other than psychiatrists. We do not believe this was the intent of Congress.

Our proposal to mandate payback would maximize the dollars spent on individuals whose training will require them to work in the shortage areas of concern to Congress.

Finally, we ask that NIMH be treated equitably in whatever figures emerge from this committee. In the past, NIMH has suffered disproportionate cuts in relation to NIH, for example, not only in terms of numbers of research grants but in other investigator-initiated mechanisms as well: Research Career Development Awards, Small Grants, Research Centers.

In fact, APA believes that NIMH should receive more favorable funding treatment to redress the existing disparity. At a minimum, we ask that NIMH receive equitable treatment in this year's appropriations.

Mr. NATCHER. Thank you very much, Ms. Strickland. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Ms. Strickland follows:]

American
Psychological
Association

TESTIMONY OF

Bonnie R. Strickland, Ph.D., ABPP

Professor of Psychology

Department of Psychology

University of Massachusetts at Amherst

and

President-Elect of

The American Psychological Association

on behalf of

THE AMERICAN PSYCHOLOGICAL ASSOCIATION

before the

UNITED STATES HOUSE OF REPRESENTATIVES

Committee on Appropriations

Subcommittee on Labor-Health and Human Services, Education

on the subject of

MENTAL HEALTH APPROPRIATIONS

May 1, 1986

2358 Rayburn House Office Building
Honorable William H. Natcher, Chair

1200 Seventeenth St., N.W.
Washington, D.C. 20036
(202) 955-7600

Mr. Chairman, Members of the Subcommittee, I am Dr. Bonnie R. Strickland, Professor of Psychology at the University of Massachusetts at Amherst and member of the National Advisory Council of the National Institute of Mental Health. I am also President-Elect of the American Psychological Association (APA), and I am pleased to testify today on behalf of APA's 87,000 members on the subject of Alcohol, Drug Abuse, and Mental Health Appropriations.

The funding levels APA proposes for ADAMHA are supported by a coalition of over 40 groups representing psychology, psychiatry, nursing, community mental health centers, consumer advocates, and many others. This is the second consecutive year that this group has developed a set of funding proposals for ADAMHA programs. In 1985, these groups coalesced as a result of the excitement generated by the findings of the Institute of Medicine (IOM) report, "Research on Mental Illness and Addictive Disorders." This year, the coalition was motivated to work together for an additional reason: to ensure that ADAMHA programs receive adequate levels of funding in FY 87 in the face of Gramm-Rudman-Hollings (GRH) Deficit Reduction Act pressures and constraints.

NIMH RESEARCH

We urge the Committee to fund NIMH Research at $272 million in FY 87. This program had been funded at $214 million in FY 86, prior to the GRH reduction of 4.3%. The Administration has proposed setting funding at the level of $194.9. The $272 million level would allow NIMH to fund 425 research grants and is in keeping with the projections of need in this area made by IOM in its report. In contrast, the President's proposal would allow NIMH to fund only 257 new and competing research grants in FY 87 -- a reduction of 62 grants from the 319 recommended by Congress for FY 86, and 168 fewer grants than the 425 recommended by APA.

This reduction in grants is the starting point for the Administration's new grant stabilization policy to achieve a constant number of total grants over the next few years. Such a reduction in grant numbers in order to "stabilize" the total grant figure has the potential to exert a serious adverse effect upon behavioral research programs. In effect, it would lower the baseline number of grants for budget consideration for years to come. This approach flies in the face of the approach of the Congress and the findings and recommendations of the mental health community and the IOM report.

The IOM report found that research studies on mental and addictive disorders need to be doubled to take advantage of new research opportunities. Last year, Congress began to address this situation by increasing support from the FY 85 level of $196.2 million to $214 million for FY 86. The Administration proposal sets back the NIMH research program to a pre-FY 85 level. APA urges this Committee to keep the NIMH research program on a forward track, instituting incremental increases over time to bring support to a productive level.

APA also recommends that NIMH be treated on a par with the National Institutes of Health (NIH) in any budget considerations. In the past NIMH has suffered disproportionate cuts in relation to Congressional treatment of NIH. For example, when the Administration proposed last year to forward fund a portion of FY 85 NIMH and NIH new and competing grants -- thereby reducing the total number of grants to be funded -- NIMH was proposed for a more severe cut proportionately. And, when Congress restored grant levels, NIH received a proportionably higher level of grant restoration than did NIMH. This has been true not only for regular research grants, but for other investigator-initiated mechanisms as well (e.g., Research Career Development Awards, Small Grants, and Research Centers). Given NIMH's documented history of underfunding, it should be receiving proportionally greater levels of increase and when reductions are necessary, it should be reduced by a proportionally lesser cut than NIH. At a minimum, equitable treatment is called for.

NIAAA AND NIDA RESEARCH

The National Institute of Alcohol Abuse and Alcoholism (NIAAA) and the National Institute on Drug Abuse (NIDA) suffer from the same underfunding as does NIMH. APA recommends that NIAAA support be increased to a level of $72 million in FY 87. NIAAA was funded at $57 million in FY 86, prior to GRH's reductions, but has a current services level of $63.7. Similarly, APA recommends tht NIDA support be increased from the FY 86 level of $74 million, prior to GRH, to $90.5 million in FY 87. The NIDA current services level is $82.6 million.

ADAMHA AIDS RESEARCH

The Administration proposes to centralize almost all AIDS research funding in the Office of the Assistant Secretary for Health in an effort to better coordinate AIDS research. We believe that the current Executive AIDS Task Force, which has representatives from all the major Federal agencies involved in the AIDS research effort, already serves this function. Further, decisions of funding priorities would be best left to the individual institutes which have the expertise and familiarity with the field to administer these funds.

ADAMHA RESEARCH TRAINING

APA recommends that the Congress appropriate $26.6 million for Research Training at NIMH. In FY 86, support for NIMH Research Training was set at $18 million (before GRH). The Administration proposes $15.8 million in support. The number of research trainees supported by NIMH has declined steadily over the past six years from a high in FY 81 of 1,350 to a projected 751 in FY 87.

This consistent decrease in numbers of research trainees funded by NIMH will make it increasingly difficult to ensure an adequate supply of well trained mental health and substance abuse researchers in the future.

In a 1985 report on the personnel needs for biomedical and behavioral sciences, the IOM advocated increased Federal support for behavioral science research training. More specifically, the report recommended increased Federal support at the predoctoral level in behavioral research. In addition, this Committee has echoed this concern in its report language for two years now, without response from ADAMHA. Instead, ADAMHA has developed a policy for 1986-87 that would require that at least 50% of total awards be made at the postdoctoral level. This policy would not only fail to increase support at the predoctoral level but would further erode existing predoctoral support. We again ask the Committee to direct ADAMHA to develop policies consistent with the recommendations of the IOM and Congress.

APA also recommends that NIDA and NIAAA's research training budgets be increased to $1.9 million and $1.8 million respectively. A continued Federal investment in training scientists in the areas of alcohol and drug abuse is necessary if we are to take advantage of current knowledge and make new inroads into what are clearly pressing national problems of substance abuse. The President's budget proposes $1.3 million for NIAAA, which would support only 63 trainees, and $1.4 million for NIDA, which would support only 68 trainees. Our request would provide for modest increases to begin to build the needed cadre of scientists in these areas.

NIMH CLINICAL TRAINING

We support funding the NIMH clinical training program at $26 million for FY 87. The Administration proposes to eliminate this program for the fifth consecutive year. In preserving this program, Congress has highlighted the need for training mental health professionals to work among such populations as the elderly, children, minorities, the chronically mentally disabled, those in rural areas, and those in jails. Congress has also encouraged NIMH to expand its successful Minority Fellowship Program (MFP). The clinical training program directly responds to these needs by requiring that trainees "pay back" the Federal government for NIMH support by working in an underserved area for each year of Federal support. Because Federal support in this area is limited by larger fiscal constraints, APA has asked the Congress to mandate that a fixed percentage - such as 75% - of clinical training funds awarded to each profession be allocated through stipends that require the individual to work in designated shortage areas.

Last year in Senate Report language that went unchanged in the Conference Committee, the Committee indicated its interest in imposing such a requirement by directing NIMH to provide the Committee with a full report on the numbers of trainees supported by the program and the percent of each discipline's funding that reflects "payback" funding. The Committee also asked NIMH to report on the overall amount of support for institutional, that is nonpayback, purposes in 1985, along with descriptions of the purposes for which such institutional support was provided.

ADAMHA recently provided the Committee with its report, and we believe this report further substantiates the need for mandating the use of the payback requirement. The report makes clear that when support goes for non-payback activities, the relationship between the use of the funds and the program's goals becomes clouded. The report notes, for example, that in the case of psychiatry, funds are used to train general medical practitioners other than psychiatrists. This is not the intent of the program. The proposal we are advocating would maximize the dollars spent on individuals whose training will require them to work in the shortage areas of concern to the Congress.

NIDA AND NIAAA CLINICAL TRAINING

NIDA and NIAAA clinical training funds were eliminated by the Administration in FY 82. The Alcohol, Drug Abuse, and Mental Health Amendments of 1984 authorized training grants in the alcohol and drug abuse areas once again. Last year, the Congress provided for $1 million of the $20 million of NIMH clinical training support to be used for training in the identification and treatment of alcohol and drug abuse. APA recommends that $1 million in support be provided for NIDA and $1 million for NIAAA to train professionals in these areas. Since 1982 many training programs have been dismantled, and at present we are facing a clear need for more personnel in these areas.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH (ADM) BLOCK GRANT

APA recommends funding the ADM block grant at $576 million with $5 million for State Planning Grants in FY 87. The Administration proposes funding this program at $490 million, which would restore it to the FY 86 pre-GRH level. However, given inflation the block grant program has suffered a $39 million reduction over the past three years. The service demands on many states have increased dramatically with the advent of such national problems as the homeless, many of whom have pressing mental health needs, and the farm crisis, which has resulted in documented increases in spouse and child abuse, alcohol abuse, and suicide. It is unrealistic to believe that the states, if faced with retrenchment of Federal support, will be able to sustain a viable level of services.

The Administration proposal would also eliminate state interagency planning grants. It is crucial that states are provided with some incentive to plan for needed comprehensive community care services for such populations as the chronically mentally disabled and the homeless. A substantial aspect of the problems encounted by these populations is the inability of the individual to negotiate access to the state and local systems at several entry points. To redress this situation states must be able to plan and coordinate a continuum of services and to provide a rational transition from in-patient to out-patient care where necessary.

NIMH COMMUNITY SUPPORT PROGRAM (CSP)

APA supports funding the CSP at $20 million in FY 87. This program was funded at $12.5 million in FY 86, prior to GRH The Administration has proposed zero funding for FY 87. CSP is an effective program for the development of state systems to coordinate service delivery, primarily for the chronically mentally disabled, the elderly, and seriously disturbed children and adolescents. The program's success is marked by the increased focus of states and localities on the needs of these target populations and by the substantial drop in hospitalization among such groups. NIMH receives a large number of applications from the states that continue to exceed available resources. Our recommended increase in support would help meet the unanswered need of many states.

MENTAL HEALTH PROTECTION AND ADVOCACY (P&A) PROGRAM

APA recommends funding the P & A program at $10.5 million in FY 87. The P&A bill has not yet reached the President's desk for signature, but the overwhelming support for the House and Senate bills argues for the President's signing of the bill. However, the Administration has proposed no funds for the program. The Act would provide for the establishment of protection and advocacy systems for the mentally disabled who are in facilities for care. These systems would allow for investigation into complaints of abuse and neglect of residents through a variety of legal, administrative and other means. The Congressional hearings on this topic revealed a pattern of abuse and neglect, and APA supports speedy implementation of the new systems.

Thank you for the opportunity to present APA's views.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

RICHARD PRUSS, THERAPEUTIC COMMUNITIES OF AMERICA

Mr. NATCHER. Our next witness is Mr. Pruss. Come around, Mr. Pruss, and you may proceed.

Mr. PRUSS. I am President of Samaritan Village, a residential drug-free treatment program in New York City.

I am past President of Therapeutic Communities of America, and currently chair its Federal Oversight Task Force.

Founded in 1975, TCA has evolved into the principal association of nonprofit residential drug-free programs in the United States, representing some 300 agencies.

Given the leadership and composition of the subcommittee, it is indeed difficult to offer that which has not been heard. The plaintive cries from "the trenches" have done little to further the plight of service providers thus far.

Incidence and prevalence data all support the view that our substance abuse problems persist. Attorney General Meese, while claiming "a measure of success," conceded that in 1984, "there was an increase in the illicit use of all dangerous drugs."

Drug abuse news continues to dominate the printed and electronic media. It was reported that Princess Margaret was amused as she watched members of the Rolling Stones sniff cocaine before a 1976 concert.

Athletes, airline pilots, politicians, physicians, Hollywood luminaries and, yes, even royalty have fueled the present fixation on the pervasive drug problem. The profusion of such reports, coupled with comprehensive coverage of dramatic and massive drug busts, serves to maintain a sense of futility among the populace.

We are losing the so-called "war on drug abuse," they conclude. This view is reinforced by the news that, with all the manpower and expense associated with interdiction, no more than 15 percent of imported drugs are seized.

Frustration over what is perceived as scratching the surface results in the inevitable pleas for legalization of marijuana, cocaine, et cetera.

While our citizens learn of the "Lifestyles of the Rich and Famous," the plight of the poor, unemployed, less educated drug abusers continues to gnaw at our social fabric. Although hardly good copy, this contingent constitutes the lion's share of the problem.

Virtually all who seek treatment enter private, nonprofit programs which rely on public funding. These agencies serve a largely indigent population with a significant concentration of minority clients.

The Therapeutic Community, TC, employs the self-help concept of treatment. TCs maintain facilities which are, for the most part, run by the clients, and conducive to personal growth. Staff serve as facilitators in an environment which, according to a 1978 NIDA report, yields "the most successful outcomes."

The "1986 Model" TC is humane, clinically sound, cost-effective and accountable. Nationwide, the average cost per day is under $40. The average spent on the purchase of drugs prior to treatment is $138 per day.

It should be noted that perhaps $1,000 must be commandeered daily by each drug abuser in order to yield the $138. We estimate that approximately $35,000,000 per year is spent by those people who, ultimately, enter TCs.

Our clients are primarily heroin and cocaine abusers. As stated above, it is a largely indigent population with many on public assistance. Moreover, for about half, placement in the TC was an alternative to incarceration, at less than one-half the annual expense.

The economy of a TC placement can be multiplied by an estimated 12,000, the approximate number of such slots utilized annually at TCA member programs. However, this number continues to fall, while waiting lists expand.

Increased costs, coupled with the prospect of level or diminished block grant funding, perpetuates the treatment dilemma. To support our efforts, it has become necessary to decrease contractual capabilities.

While this would seem to address operating deficits, our reluctance to keep beds unfilled translates into overcrowding and, ultimately, greater deficits.

For example, in the Commonwealth of Massachusetts, the average utilization for residential drug-free programs for the first half of fiscal year 1985 was 124 percent.

Those who seek help of a Therapeutic Community are considered without regard to their ability to pay for treatment. Our admission policies are inclusionary. Staff, while historically underpaid, are compassionate, committed professionals who are dedicated to humane and sound treatment and an improved social condition.

We continue to adapt to changing patterns of drug abuse and the changing profile of the drug abuser. Simply put, we are doing the best we can, given existing resources. However, "the best we can" is not good enough.

Substance abuse among the elderly is an issue largely unaddressed. Prescription drug abuse within this population is a growing problem. Education and self-help programs are needed.

Adolescents are underserved. In Rhode Island, for example, an adolescent male who requires residential drug-free treatment is out of luck. There is no resource.

That intravenous drug users are a high-risk group for AIDS is clear. In a recent study in New Jersey, it was found that of all such cases reported, 45 percent were heterosexual intravenous drug abusers. By April 1985, almost 600 cases had been diagnosed in New Jersey.

As legions of health professionals shun the AIDS patient, not one staff member has left the employ of Marathon House out of fear of contracting the disease. Clients are treated with respect and sensitivity, not with revulsion and household bleach.

The combination of the therapeutic community approach and respite care for our afflicted clients is a proposition which ought to be pursued. The Centers for Disease Control tell us that we are still seeing "geometric" growth in the incidence of AIDS.

There are no magic cures. The reclamation of a human spirit takes time and hard work. In this field, miracles are few and far between. One is reminded of the cure discovered for morphine addiction. It was deemed safe and non-addictive. Its name was testimony to its miraculous introduction: Heroin.

Celebrities enter the Betty Ford Clinic, while dope fiends enter "a drug treatment program." Athletes, actors and rock stars have "drug problems," while the indigent are "addicted." Curiously, physicians are deemed "impaired."

We nonprofits are egalitarian. It is that which our clients have in common which provides the impetus for treatment. To confront one's personal deficits is often painful, but there is no easy way out, especially for the hard core.

The President has recommended that $490,000,000 be appropriated for fiscal year 1987 under the Alcohol, Drug Abuse and Mental Health Block Grant. This reflects the restoration of dollars cut via the Gramm-Rudman-Hollings legislation, this returning to the fiscal year 1985 level.

While we are grateful that the President seeks this restoration, it should be noted that, when adjusted for inflation, there has been a 45-percent reduction in Federal support for such services since fiscal year 1980.

In summary, all of us in the prevention, education and treatment sectors need your help. It is urged that the full amount authorized for the ADMS Block Grant Program, $576,000,000, be appropriated.

With your advocacy, the sense of futility which pervades the taxpaying contingent will give way to a spirit of celebration. Our victories are demonstrable and dramatic. Our commitment unwavering. Our potential limitless. Again, many thanks for the honor of offering the present testimony.

Mr. NATCHER. Thank you, Mr. Pruss. You made a good statement. We appreciate your appearing at this time.

THURSDAY, MAY 1, 1986.

NIH AND ADAMHA

WITNESS

DR. MYRON GENEL, PUBLIC POLICY COUNCIL OF THE AMERICAN SOCIETIES OF ACADEMIC PEDIATRICS

Mr. NATCHER. Our next witness is Dr. Myron Genel. Come around, Dr. Genel, we will be pleased to hear from you at this time.

Dr. GENEL. I was listed to be speaking primarily for ADAMHA, and to correct the record, I am speaking on behalf of all of the appropriations at NIH and ADAMHA.

I am Myron Genel, Professor of Pediatrics at Yale University. For the past 15 years, I have also served as Program Director of the Programs at the Children Research Center, supported by NIH funds.

I speak to you today representing the American Pediatric Society, the Association of Medical School Pediatric Department Chairmen, and the Society for Pediatric Research in my capacity as Chairman of the Public Policy Council.

These organizations represent pediatric researchers, the faculty of medical and research facilities, and the leaders of all U.S. medical school pediatric departments. Membership in the American Pediatric Society and the Society for Pediatric Research is conferred on the basis of scholarship, research and contributions to pediatric education.

What I would rather do today is to share with you a vignette of experience which happened to me while driving, while traveling to Washington today.

I happened to be seated on an airplane next to a gentleman who informed me that 13 years ago, his son, while 2 years of age, had been a patient at our clinical research center, and he had two days before been diagnosed as having leukemia, and was told standard therapy available at that time could offer his family and the child the opportunity for six months of useful life.

That boy is now 15 and a starting player on the football team for his high school, the beneficiary of research in cancer that has been provided by the NIH, and by programs such as the General Clinical Research Center supported by the NIH.

I can find no better demonstration of the value of research that has been devoted to providing better therapy for children than—for the children of our country than this simple story, which happened on the way down here today.

I will summarize my statement by indicating the support of our organizations for the recommendations of the Ad Hoc Group for Medical Research Funding, and we agree with the recommendations for levels of $6,579,000,000 for the NIH, and $465,000,000 for ADAMHA.

Within these levels, we urge you to provide enhanced support for the training and development of physician investigators, and for support of the General Clinical Research Centers Program, which supports programs such as the one which I have just informed you about at Yale.

We also encourage the development of a cross-agency study to determine the levels of Federal biomedical research which involve infants and children, and urge there be a continuation of primary care training grants at present levels.

These programs represent opportunities for Congress, the medical profession and our society, to invest in tomorrow in a way which will result in a healthier population, and also physically sound.

Preventive medicine is accepted as the most cost-effective, cost-beneficial health plan, and biomedical research and training of health professionals is part of preventive medicine.

Mr. Chairman, I thank you.

Mr. **Natcher**. Thank you very much, Doctor. You made a good statement.

[The statement of Dr. Genel follows:]

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TESTIMONY

before the

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

on

NATIONAL INSTITUTES OF HEALTH

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

PRIMARY CARE TRAINING

PRESENTED BY

MYRON GENEL, M.D.

May 1, 1986

2:40 p.m.

SUMMARY OF RECOMMENDATIONS

PUBLIC POLICY COUNCIL

of the

American Pediatric Society
Association of Medical School Pediatric Department Chairmen
Society for Pediatric Research

As organizations representing pediatric researchers, the faculty of medical and research facilities and the leaders of all U.S. medical school pediatric departments, the American Pediatric Society, the Association of Medical School Pediatric Department Chairmen, and the Society for Pediatric Research appear today to speak on behalf of future generations of America's infants, children and adolescents. Recognizing and accepting the need for fiscal constraint and responsibility should not force Congress to jeopardize the health and well-being of our future by decimating today's health programs. Tomorrow's children will the beneficiaries of monies spent on today's biomedical research.

These organizations submit the following recommendations:

1. We fully support the recommendations of the Ad Hoc Group for Medical Research Funding for fiscal year 1987 levels of $6.079 billion for the National Institutes of Health and $465 million for the Alcohol, Drug Abuse, and Mental Health Administration.

2. Within these levels, there should be enhanced support for the training and development of physician investigators and for the General Clinical Research Centers program.

3. We encourage the development of a cross-agency study of federal biomedical research involving infants and children.

4. There should be a continuation of primary care training grants at present levels.

These programs represent opportunities for Congress, the medical profession, and our society to invest in tomorrow in a way which will not only result in a more healthy population, but which will also be fiscally sound. Preventive medicine is accepted as the most cost-effective, cost-beneficial health plan; biomedical research and health professions training is preventive medicine.

Mr. Chairman, I am Myron Genel, M.D., professor of pediatrics at Yale University. I speak to you today representing the American Pediatric Society, the Association of Medical School Pediatric Department Chairmen, and the Society for Pediatric Research in my capacity as Chairman of the Public Policy Council. These organizations represent pediatric researchers, the faculty of medical and research facilities, and the leaders of all U.S. medical school pediatric departments. Membership in the American Pediatric Society and the Society for Pediatric Research is conferred on the basis of scholarship, research, and contributions to pediatric education.

During these difficult days of fiscal restraint and need for deficit cutting, we must all make sacrifices. Our organizations recognize this necessity. Our plea today is that this Congress will remember the infants and children of today, and perhaps more importantly, those of the future, as a population which cannot be forgotten. It is unfair to expect this Congress and the American people to decide which children will be helped and which children forgotten. It is even more unfair for Congress to decide to halt the revolutionary progress towards full and productive lives for all Americans.

Further, the members of our organizations realize that the worlds of politics and science are often in conflict over the future and direction of policies affecting biomedical research. Even in such conflict we should all agree that the goal of biomedical research is to improve the health of people. As pediatric researchers and educators we believe that improving the health of people begins with improving the chance of infants and children to be born healthy and to grow and develop into adulthood.

I RESEARCH

Congress and the American people have demonstrated support for continued biomedical research. No one will deny that the research advances in biological and medical sciences have led to the prevention and cure of countless previously intractable conditions. Congress has displayed an understanding of the need for such research and the wisdom to invest in the future through upholding financial support for such research, especially through the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). Nonetheless, there has not been an increase in actual purchasing dollars for several years.

The statistics are available which attest to the value of the research. The survival rate of childhood cancer victims rose from five percent in 1962 to 57 percent in 1982, a span of only 20 years. Smallpox has been eradicated and polio has been arrested. Systematic vaccinations for diphtheria, whooping cough, tetanus, mumps, measles, rubella, and haemophilus meningitis have increased a child's opportunity to become a healthy adult. Diarrheal diseases and malnutrition are no longer an unavoidable threat to infant survivability. We now know that some victims of Sudden Infant Death Syndrome have subtle defects of a neurologic, cardiorespiratory and/or metabolic nature, which if detected early may be life-saving. Many childhood injuries are recognized as preventable. Genetic and biological research has greatly expanded our ability to understand the cause and help the 200,000 infants born each year with congenital abnormalities.

Research benefiting infants and children stands at an important crossroads. If we are farsighted, we can take advantage of recent developments and build upon them. We can continue to stride forward towards increasing our infants' survivability, ensuring treatment for children with cancer, reducing the risk of cancer (one out of every three babies born in 1985 will develop cancer during its lifetime), improving treatment for diabetes, arthritis, cystic fibrosis and other even more debilitating diseases, and providing hope for the families of the two million children who have mental disorders so severe they require immediate care. If we choose to hesitate, we will see children suffer.

For example, despite all of our medical and technological advances, the United States still has an unacceptably high infant mortality and morbidity rate, primarily due to premature and low birthweight babies. These babies account for 70 percent of neonatal deaths. These premature and low birthweight infants have the greatest struggle and face the highest chances of death or lifelong disability. Furthermore, the intensive care and hospital care alone for these babies cost $6.5 billion each year, not to mention the profound cost, both personal and societal, of the residual disabilities. Of those infants who survive, many suffer handicaps, such as mental retardation, cerebral palsy, seizures, learning disabilities, blindness and deafness. Unfortunately, these handicaps are usually non reversible and the victim and the victim's family spend a lifetime coping with his or her life. Respiratory distress syndrome, characterized by lung immaturity and caused by an insufficiency of a substance, surfactant, which lines the airspaces and prevents lung collapse, is a common cause of illness of premature infants. Investigation is in process to determine if administration of this substance, which has been obtained from calves and may soon be available through genetic engineering techniques, may provide successful treatment of respiratory distress syndrome.

The National Institutes of Health supports research into all areas of pediatrics. Research for children is designed 1) to advance our knowledge of genetics, including how best to use that knowledge; 2) to investigate fetal development, pregnancy, birth, and infant morbidity and mortality; 3) to identify the prerequisites of optimal growth from infancy to adulthood; 4) to contribute to the prevention and treatment of critical problems for children such as cancer, respiratory diseases and disorders (i.e., allergies, asthma, and respiratory distress syndrome), infectious diseases, diabetes, mental retardation, and cardiovascular, pulmonary and blood diseases; and 5) to better understand the psycho-social attitudes of behavior, including those which endanger the health and safety of children.

Research for infants and children needs more than our moral support; it needs your financial support. Endowment funds and private donations provide significant pediatric research support in only a handful of institutions and those foundations which provide specialized pediatric research are relatively small. Congress must be cognizant of the fact that most pediatric research funds come from the federal government, namely the National Institutes of Health. However, in 1983, the National Institute of Child Health and Human Development allocated only 11 percent of their research project grants and 17.1 percent of their funds to pediatric departments for research involving infants and children; most the Institute's remaining funds went to maternal health and reproduction. Other Institutes contributing significantly to pediatric research include the National Institute of Allergy, Immunology, and Infectious Diseases (4.5 percent of its grants), the National Institute of Arthritis, Digestive and Metabolic Disease (3.1 percent of its grants), the National Heart and Lung Institute (3.2 percent of its grants) and the National Cancer Institute (1.4 percent of its grants).

The important role of the General Clinical Research Centers (GCRC) program of the Division of Research Resources within the portfolio of pediatric research must be noted and supported. Pediatric research places particular emphasis on clinical research providing the promise of direct benefit for infants and children. The GCRC program provides support for clinical research at 78 centers, 16 of which are devoted primarily, if not exclusively, to pediatric clinical research. In 1983 pediatric research accounted for 30 percent of the GCRC program budget and 30 of the 100 graduates of the GCRC clinical associate physician program, a primary source for training physician investigators, have been pediatricians.

We feel that adequate provision for research training, both individual and institutional programs, is essential for the development of the next generation of basic science and clinical investigators. The recent 1985 report by the Institute of Medicine, "Personnel Needs and Training for Biomedical and Behavioral Research," assessed these training programs. This report reinforces the need for federal support of research training programs at a time when medical schools, colleges and universities are "encouraging" all departments to become revenue-producing through increased provision of health services rather than concentrating on non-revenue-oriented research. Physician investigators are being used more in the clinical setting providing health services. It is important to recognize the need for and value of physician investigators in basic research. Physicians are necessary to provide patient management whenever pediatric patients are being used in a research program; they are important in interpreting and applying knowledge gained through research to the practice setting; they are critical in identifying the direction of research and the needs of pediatric patients. The level and distribution of training funds supplied by the federal government should be maintained at a level which will achieve a stable and efficient system. Quality researchers are not produced in one year; a typical training program can last seven to ten years. Sharp variances from year to year will be disruptive. The Institute of Medicine report strongly urged that training positions not be decreased.

The American Pediatric Society, the Association of Medical School Pediatric Department Chairmen, and the Society for Pediatric Research recommend for fiscal year 1987 that the funding for NIH reflect the need for program balance in order to accomplish the missions of the various Institutes, to support basic and applied research, and to train qualified investigators. To this end we join with the Ad Hoc Group for Medical Research Funding in recommending a 1.4 percent increase over the current services budget which would bring FY87 NIH funding to $6.079 billion.

When considering medical research programs, Congress should also remember the critical role the Alcohol, Drug Abuse and Mental Health Administration plays in furthering our knowledge of health problems today. This agency funds multi-faceted biomedical, behavioral and developmental research activities, attacks the increasingly serious problem of substance abuse, trains investigators, and assists the transfer of life-prolonging clinical knowledge and technology to the general public. To accomplish necessary growth for ADAMHA, our organizations support the recommendation of its colleagues through the Ad Hoc Group for Medical Research Funding of $465 million for fiscal year 1987.

While recognizing the significant accomplishments of federal support for pediatric research, it must be noted that approximately three percent of all NIH research grants and funds are awarded to pediatric departments. There is a compelling need for an in-depth study of research relevant to infants and children supported by federal agencies. This would provide a clear overall picture of what is being studied, where the gaps are, how the research is being translated into improved pediatric practice and improved child health, and where future pediatric research should be focused.

II PRIMARY CARE TRAINING

Primary care is the most cost-effective way of providing health care since it has the potential to reduce the need for expensive tertiary consultation and inpatient care. Most primary care pediatricians see patients on an ambulatory basis.

Unfortunately, primary care residency programs have enormous difficulty in obtaining the financial support they need to train primary care physicians. Traditionally, specialties with high levels of tertiary care and procedure-oriented, hospital-based practices have received disproportionate hospital, medical school and third-party payer support for residents. This is in large part because of the revenue generated from their procedure-oriented, inpatient services. Hospitals allocate more residency positions in those specialties which bring in needed revenue. Since training programs for the most cost-effective form of health care delivery -- primary care --cannot achieve even inadequate financial support, federal support is essential to allow quality primary care education to continue. Evidence is clear that the programs and trainees funded by grants under Title VII of the Public Health Service Act have been highly successful. Loss of grant support for primary care training programs could end with a reversal of many gains in physician distribution and could shift emphasis back to subspecialties.

Therefore, our organizations recommend that funding for Title VII, primary care training grants for general pediatrics and internal medicine be kept at the current level of $18.5 million.

Mr. Chairman, in summary, the American Pediatric Society, the Association of Medical School Pediatric Department Chairmen, and the Society for Pediatric Research wish to state once again that in spite of national concern over budget deficits and Congressional pledges to attack that deficit, there are some compromises which cannot be made. Expanding and improving health research programs for infants, children and adolescents and promoting primary care is not inconsistent with controlling health costs. Supporting these programs simply increases the opportunity to need less financial commitment for future health problems as well as providing a healthy and encouraging outlook for future generations.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

RICHARD A. DEITRICH, DIRECTOR, ALCOHOL RESEARCH CENTER, UNIVERSITY OF COLORADO HEALTH SCIENCES CENTER

Mr. NATCHER. Our next witness is Dr. Richard A. Deitrich, and we will be pleased to hear from you at this time.

Mr. DEITRICH. Thank you, Mr. Chairman.

I am appearing on behalf of the Research Society on Alcoholism, of which I am a past president. The Society has nearly 500 members who are active alcohol researchers. Their goal is to achieve an understanding of alcohol effects so that better methods of prevention and treatment of alcoholism can be accomplished.

I am also Scientific Director of the University of Colorado Alcohol Research Center. Our work is primarily in the area of the influence of genetics on the responses of people to alcohol. In addition, we have a large animal genetic study which is a model for much of the work in animal genetics in alcohol research currently ongoing.

The whole area of the relationship of genetics and alcoholism appear to be poised on the brink of major new understanding and consequently better methods particular of prevention.

I wish to thank the committee for the opportunity to submit my views on the budget for the National Institute on Alcohol Abuse and Alcoholism, and I wish to urge the committee, and eventually the House of Representatives, to continue to strongly support the budget for NIAAA. Your support in the past has been much appreciated and vital to the progress that has been made.

While I am sure that you are all aware of the tremendous toll in human lives and economic loss caused by alcohol abuse, perhaps it would be of some use to reiterate those statistics here.

The cost in human lives is nearly 100,000 per year, many from traffic accidents, but many more from other complications of alcohol abuse.

Nearly one in three individuals in the country is affected in some way by alcohol, either because they are alcoholic themselves or because a close family member has a problem with alcohol.

The dollar cost is over $116,000,000,000 each year. The fiscal year 1987 President's request of $56,618,000 for NIAAA research is only less than half a cent for every dollar that alcohol abuse costs.

A better opportunity for cost-effective research would be hard to find, since even a small percentage reduction in the cost will pay for itself very quickly.

Should the President's request hold, the impact on the NIAAA programs would be devastating. It would allow for only 64 new and competing grants and, in addition, require a cut of 16 percent in the funds for those.

In a young and growing field of research endeavor, the infusion of new ideas and new people is vital to its eventual success. Such drastic cuts would raise the doubts in the minds of new investigators of the advisability of entering the field.

In our case at the University of Colorado Alcohol Research Center, we would be forced to further curtail our studies on the human genetics of alcohol actions as well as terminate some preliminary but promising leads in the molecular genetics of alcohol action in animals.

The proposed budget would also result in fewer trainees just at a time when infusion of new talent into the field is most needed. Obviously, the trainees of today will be the researchers that we must have in the next few years if we are to ever bring the problem under some control.

The areas of promising new leads that could be exploited or that require increased research are, in my view, the area of genetics ranging from molecular genetics to human inheritance of genetic predisposition to alcoholism, application of new imaging techniques and much increased efforts in the areas of immunology, as exemplified by the new problems of AIDS among the alcohol abusing population.

At the recent meeting of the Research Society on Alcoholism, NIAAA sponsored a symposium on the use of new imaging techniques such as nuclear magnetic resonance that are providing fantastically detailed pictures of the brain.

These techniques have the capability to detect structural damage and even biochemical abnormalities caused by alcohol in humans in detail unobtainable just a few years ago. New techniques of analysis of brain waves hold the possibility of being able to identify children at risk for development of alcoholism.

At other sessions of that meeting, first-rate research was presented on nearly every aspect of biomedical and psychosocial research. The great bulk of the research is supported by NIAAA through its regular grant program, the Alcohol Research Centers, its training grants and the intramural research program.

Not so many years ago, before the establishment of NIAAA, alcohol research meetings were nonexistent, little was being done at the basic biomedical level to establish the causes of alcohol damage or way to prevent such damage.

Alcohol research has turned its attention to the area of infectious diseases in recent years, primarily because of the notoriety of AIDS. It has been known for years, however, that alcoholics were much more susceptible to infectious diseases, but the new problem of AIDS makes research in this area even more critical.

The question of why alcohol intake is damaging to the immune system and the mechanism of this effect must receive increased attention and will call for expansion of alcohol research into immunology more extensively.

Thus, I would urge adoption of the recommended level of $88,200,000 for NIAAA and an increase of 13 positions. Even that amount is but a small fraction of the amounts allocated to research on less prevalent diseases among our population, but would allow for orderly growth in the research programs, but at the intramural and extramural levels.

Related to the mission of NIAAA are the budgets of NIMH and NIDA. I would urge that they be funded at a level of $272,000,000 and $90,500,000, respectively.

Mr. **Natcher**. Thank you very much, Dr. Deitrich. You have made an excellent statement. We appreciate your appearance before the committee.

[Mr. Deitrich's statement follows:]

Statement by Richard A. Deitrich, Ph.D.
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I wish to thank the Committee for the opportunity to submit my views on the budget for the National Institute on Alcohol Abuse and Alcoholism and I wish to urge the Committee, and eventually the House of Representatives, to continue to strongly support the budget for NIAAA.

While I am sure that you are all aware of the tremendous toll in human lives and economic loss caused by alcohol abuse, perhaps it would be of some use to reiterate those statistics here. The cost in human lives is nearly 100,000 per year, many from traffic accidents but many more from other complications of alcohol abuse. Nearly 1 in 3 individuals in the country is affected in some way by alcohol, either because they are alcoholic themselves or because a close family member has a problem with alcohol. The dollar cost is over $116 billion each year. The fiscal year 1987 President's request of $56.618 million for NIAAA research is only less than half of a cent for every dollar that alcohol abuse costs. A better opportunity for cost effective research would be hard to find, since even a small percentage reduction in the cost will pay for itself very quickly.

Should the President's request hold, the impact on the NIAAA programs would be devastating. It would allow for only 74 new and competing grants and, in addition, require a cut of 16% in the funds for those. In a young and growing field of research endeavor, the infusion of new ideas and new people is vital to its eventual success. Such drastic cuts would raise the doubt in the minds of new investigators of the advisability of entering the field.

The proposed budget would also result in fewer trainees just at a time when infusion of new talent into the field is most needed.

The areas of promising new leads that could be exploited or that require increased research are, in my view, the area of genetics ranging from molecular genetics to human inheritance of genetic predisposition to alcoholism, application of new imaging techniques and much increased efforts in the areas of immunology, as exemplified by the new problems of AIDS among the alcohol abusing population.

Thus, I would urge adoption of the recommended level of $77.2 million for research and $1.8 million for training for NIAAA. Even that amount is but a small fraction of the amounts allocated to research on less prevalent diseases among our population but would allow for orderly growth in the research programs, both at the intramural and extramural levels.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

DR. DAVID C. LEWIS, PROFESSOR OF MEDICINE AND COMMUNITY HEALTH, BROWN UNIVERSITY

Mr. NATCHER. Our next witness is Dr. David C. Lewis, and we will be pleased to hear from you.

Dr. LEWIS. I am a Professor of Community Health at Brown and past President of the Faculty Group that teaches about drug and alcohol at the medical schools in this country, and was on the National Advisory Council, so my written testimony talks about the budget for NIAAA.

What Roger Meyer and Dr. Deitrich said are what I would echo, so I won't repeat that. We have to cut somewhere between what the Institute of Medicine and the President are recommending.

The momentum is an issue here, particular at NIAAA. In the last two years, we made some progress, and to backtrack now would be very discouraging, in terms of what will happen to the research community in their response to being—submitting excellent grants and not being able to get them funded.

A couple of areas I am familiar with. One would be the research training and the other would be the clinical training.

Without the usual remark of the importance of research training, I am going through that cycle of frustration, having submitted a research training grant and had it approved by the rigorous peer review process, having a high priority score and the research training and intervention research which is the kind of research that some of the people on this committee would like to see done, the patient outcome, treatment outcome research kind of training, and yet it is quite doubtful that the money would be in the NIAAA budget to support that grant.

That will be frustrating, and we have a waiting time. We have a committed faculty at Brown, and we can resubmit it. Our story is similar to many faculties throughout the country. There is a time in which faculty will drift away from this and say, hey, we will do something different, so I am worried about that.

The same thing applies to basic researchers for submitting grants for RO-1s, so the need is not only to sustain the momentum in the basic research budget, but to pay attention to some of these clinical training areas.

That has been $1,000,000, and I want to point out that I think both NIAAA and NIDA have made some very good use of those limited funds.

I have recommended $1,000,000 be placed in the line item budget of NIDA and NIAAA instead of doing it through the NIMH appropriation.

I participated in a public-private partnership activity sponsored by the Association for Medical Education and Research in Substance Abuse, which held its National Conference last November, and it was cosponsored by NIDA, NIAAA, the Betty Ford Center and the Annanberg Center, and we had some participants who were the leaders in medical education, and Mrs. Ford participated in that conference herself.

From that conference, we reached a consensus on what every primary care physician should know, and that has been distributed to all medical school deans and to our membership, and to chairmen of departments throughout the country.

I am using it as an example of a small number of Federal dollars used to leverage up a large process nationally that is primarily in the private sector.

What is happening now with this consensus about what every physician should know in the diagnosis of drug and alcohol problems is that there are four national professional societies working to refine these general consensus statements to be discipline-specific in family medicine, internal medicine, psychiatry and pediatrics, a good example of Federal money well spent.

So I am recommending that appropriations be made again, and be a specific line item.

Last, patient placement research or treatment outcome research, I know Mr. Conte has had an interest in this in the past, and I have reviewed the report that was submitted through ADAMHA on the subject of treatment research, and it is an excellent and cogent report.

So it would be a good guideline for the committee to look and compare future developments against.

The Brown faculty is very interested in this particular area of research, and we have been interested in research training and the research itself. To see the need for this kind of research at a local level as well as national is very interesting for me.

We were recently asked by the State of Rhode Island to prepare a report on the status of substance abuse treatment in Rhode Island, and I have a copy if you would like to see how States go about this, and what data they need and don't have.

As part of this report, we did a prevalence study, saying how much of a problem the need was in the community, and alcoholism and other forms of substance abuse. The report dealt with defining what treatments worked and didn't work, and in this report there is a chapter—the policymakers were waiting for the answer in this report.

We had a certificate of need law, and they had to make some decisions, and they had hoped that we would come up with some kind of a matching with treatment programs to patients.

The review of that was inconclusive, and the policymakers were frustrated, and we are now trying to go ahead and build a statewide research study for this purpose.

If we do that, there is no way we can possibly pull that off with private resources, and we will have to prepare a grant in the usual fashion for peer review, submit it to the Federal Government.

The grant would probably take three to five years to conduct. The reason for bringing this up is two-fold: A good example of pure scientific basis, what works and what doesn't, but today we need to know what to approve, disapprove, and there is a pressing need for it.

The research, to be worth anything, has to be peer reviewed. It takes a long time, and it is very expensive, much more so than the average RO-1, so that I am very pleased that members of this committee are interested in this kind of research, as we are. To be able to transfer the interest into actual accomplishment is going to be difficult.

It is expensive, but the more aware the committee is, both as an impetus to general increasing research support for NIAAA—and it is a privilege to be back again.

[The statement of Dr. Lewis follows:]

STATEMENT OF

DAVID C. LEWIS, M.D.

PROFESSOR OF MEDICINE AND COMMUNITY HEALTH

AND DIRECTOR, CENTER FOR ALCOHOL STUDIES,

BROWN UNIVERSITY

PAST PRESIDENT, ASSOCIATION FOR MEDICAL EDUCATION

AND RESEARCH IN SUBSTANCE ABUSE (AMERSA)

BEFORE THE

HOUSE COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION, AND RELATED AGENCIES

MAY 1, 1986

David C. Lewis, M.D.
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Mr. Chairman and Members of the Subcommittee:

My name is David C. Lewis, M.D. I am Professor of Medicine and Community Health at Brown University and Director of the Brown University Center for Alcohol Studies. I am also the Past President for the Association for Medical Education and Research in Substance Abuse (AMERSA). AMERSA is the 400 member national faculty organization whose members are primarily focused on the education of medical students, house staff, and practicing physicians in the area of substance abuse and chemical dependence. Brown University currently provides a national office for AMERSA.

I am familiar with the budgets of NIAAA and NIDA, having completed a four year term as a member on the National Advisory Council to NIAAA and Liaison Advisory Council member to the NIDA Council. In my term as an Advisory Council member I was impressed with the quality of research applications to both of these institutes and have felt, particularly in the last few years, that our ability to fund quality research was impaired by chronic underfunding of the research budgets for both of these institutes. The estimates of a Research Triangle Institute study that the cost of drug abuse to our society in 1983 was over $59 billion and that for alcohol abuse and alcoholism was over $116 billion put into further perspective the necessity for adequate research funding. In the last several years I have concentrated in my professional work more on the problems of alcohol use and alcoholism and have worked most closely with NIAAA. For that reason, I have made specific recommendations primarily concerning the NIAAA appropriation.

I also wish to comment on two areas of particular interest to me - 1) the continuuing federal role in the clinical training of medical professionals and 2) the importance of treatment outcome research. On this latter point, I know that Mr. Conte and the Committee have been interested in the status of treatment outcome research. I have had the opportunity to review the document entitled "Report on Alcoholism Treatment" that Mr. Robert Trachtenberg, on behalf of ADAMHA, submitted to this Committee in February, and I can attest to the excellence and cogency of that report.

Concerning the NIAAA appropriation, following on a period of growth for the alcohol research program, the FY 1987 President's Budget represents a severe setback in our goals of sustained, moderate growth of the research program, as well as our goals for viable research training programs.

I believe that the NIAAA needs an additional $19.2 million over the FY 1987 President's Request to meet funding shortfalls and to assure a moderate level of growth for alcohol research. The additional funding I am recommending includes $15.4 million for research; $.5 million for research training; $1.0 million for clinical training; and $2.3 million for direct operations. This would provide a total of $88.0 million. The total for research and research training would be $73.8 million, still considerably short of the most recent recommendations of the Institute of Medicine (IOM). In a 1984 report on ADM research, the IOM recommended that NIAAA's research and training budget be increased to $100.0 million in constant 1983 dollars. Implementation of the IOM recommendation would require $116 million in FY 1987 dollars.

Research Grants

The FY 1987 budget reflects OMB's decision to stabilize the total number of research grants at approximately the FY 1986 level and to maintain the average cost of grants at a prescribed level, determined by adding an inflation factor to the FY 1985 average cost. This policy works a special hardship on NIAAA's grant program because it locks the program into a specific average cost which is calculated on an erroneously low base, and a specific number of grants which does not take into account the increased committments for continuation awards.

Because a shortfall existed in FY 1985, new and competing grants were cut by 10 percent and continuations were cut by 5 percent. Thus, by basing the FY 1987 average cost calculation on FY 1985 actuals, the problem of having to reduce individual grants is carried into FY 1987. It is estimated that continuing investigator-initiated research grants (ROIs) will have to be cut by 3 percent and new and competing investigator initiated grants by 17 percent. The FY 1987 budget allows an average cost of only $100,000 for new and competing awards, compared to $132,000 for ADAMHA as a whole and $154,000 for NIH. It will require an additional $2.2 million to restore the continuation awards to full Council-recommended levels and to provide a more realistic average cost ($119,000) for the 74 new and competing awards.

The total number of grants allowed by the FY 1987 budget is 270, approximately the same number as in FY 1986. However, due to the growth experienced over the past few years, the number of continuations has increased each year. Thus, stabilizing the total number of grants requires a reduction in new and competing awards. In FY 1987, the number of continuations increases by 24; the number of new and competing is reduced by 26 from the FY 1986 level. The budget allows for only 74 new and competing awards, compared to 100 in fiscal years 1985 and 1986. It will require an additional $2.8 million to restore the number of new and competing grants to the previous level of 100.

The steps described above would restore NIAAA's grant program to a current services level. However, it is clear that an increase over this level can be used effectively. More investigators are becoming interested in alcohol research, and if the field is to build on the remarkable achievements of the last few years, it is crucial that the grant program be allowed at least a modes level of growth. We are recommending an increase of at least 16 percent over the FY 1986 level, in the number of new and competing grants. This would require an additional $1.7 million for 16 new grants, at an average cost of $107,000. We are also recommending that funds be added to allow for at least 3 of the 16 new grants to be large grants. Ther are some unusual needs in the alcohol field that require expanded support. For example, NIAAA has a responsibility to take on a comprehensive program of treatment assessment research. This type of research is expensive and simply cannot be done adequately unless some flexibility is added for the more expensive projects. An additional $1.2 million is needed to provide for this need.

In summary, an additional $7.9 million is needed for research grants, as follows:

-- $2.2 million to restore noncompeting projects to Council-approved levels and provide a more realistic average cost for new and competing grants

-- $2.8 million to restore the number of new and competing to 100, the same number as in fiscal years 1985 and 1986 (26 additional grants)

-- $1.7 million for an additional new 16 grants, to provide growth of 16 percent over FY 1986 new and competing

-- $1.2 million to allow 3 of the new grants to be unusually large, in order to meet special needs in such areas as treatment assessment research

Other Research Mechanisms

The emphasis over the past few years on investigator-initiated grants has been crucial to development of the field. However, it has required some serious constraints in other areas. The Centers Program has never been allowed to reach its full potential; the lack of sufficients funds for contracts has resulted in very minimal efforts to develop a comprehensive epidemiological data program; and severe restrictions on new RSDAs and small grants has greatly hampered NIAAA's efforts to attract new investigators. We are suggesting that funds be added as follows:

-- $.8 million to provide some expansion in the 9 existing Centers

-- $3.0 million to fund 2 new Centers on Alcohol and Immunology (including AIDS) and Alcohol and High Risk Populations

-- $.2 million for 5 new RSDAs, to increase the total number to 29

-- $.1 million for 10 small grants, to increase the total number to 20

-- $.4 million to provide some expansion to epidemiology and other research contracts

-- $.1 million to increase Small Business Innovation Research (SBIR) set-aside to correspond to the recommended extramural research funds

Intramural Research

The intramural program received a dollar increase in the FY 1987 budget to enable it to meet mandatory increases, primarily related to the clinical program located at NIH. The program is allowed no growth and, in fact, suffers a program reduction of $.2 million in equipment funds. There are two major needs that are not met by the budget. First, the program must be allowed to replace obsolete equipment, and second, the program must be allowed to more fully develop its NMR research capabilities. Last year the Congress added funds to allow NIAAA to participate in the development of the new NMR facility at NIH. Additional funds are needed in FY 1987 to continue and expand this effort. An additional ~~$2.9~~ million is needed, as follows:

-- $.7 million to restore the cutback in equipment funds and allow for additional purchases to replace obsolete equipment

-- $.6 million to provide continuation costs of the NMR research begun in FY 1986

-- $1.6 million to allow NIAAA to hire personnel (8 positions) and purchase equipment needed to take full advantage of the research opportunities afforded by the NMR facility

Research Training

There has been a steady decline in the training program. Budget cuts and stipend increases over the years have resulted in decreased in the number of people trained, so that by FY 1986, only 66 trainees are supported. This will be reduced to 63 under the Administration's FY 1987 budget. Research training support in all health research Institutes has declined steadily since FY 1982. However, NIAAA, as well as ADAMHA as a whole, had such a low base in FY 1982 that the cuts have been disastrous. In FY 1982, the NIH supported 91 percent of the trainee level recommended by the National Academy of Sciences (NAS); the Administration's request for FY 1987 will allow NIH to support 88 percent of the trainees recommended by the NAS. ADAMHA supported only 65 percent of the trainee level recommended by the NAS in FY 1982; under the Administration's request, this will fall to 50 percent of NAS recommendations by FY 1987.

For NIAAA research training, the budget requests only $1.3 million for research training. This is only 2 percent total research and research training funds. A more reasonable distribution, and one more in line with the distribution of funds at NIH, would be 6 percent research training. If training program must be allowed to begin a longer-term growth of research trainees to a level that is consistent with the level of research funding. It is suggested that 80 trainees would be an appropriate level for FY 1987. This would provide a beginning towards an adequate level of support. An additional $.5 million, for 17 addition trainees, would be required to achieve this goal in FY 1987.

Clinical Training

NIAAA's clinical training program was dismantled in 1982. However, the Alcohol, Drug Abuse, and Mental Health Amendments of 1984 (P.L. 98-509) authorize grants to support the training of health professionals in the identification and treatment of alcohol and drug abuse problems. P.L. 98-509 also requires that NIHM clinical training funds be used for this purpose in FY 1985. In FY 1985, NIMH clinical training funds totalling $250,000, supplemented by funding from the direct operations line item of NIDA and NIAAA, provided for 4 projects to conduct a needs assessment and develop a comprehensive educational strategy for integrating alcohol and drug information into education of health care providers.

The Report accompanying the FY 1986 appropriation for ADAMHA directs the agency to use $1.0 million of appropriated clinical training funds for alcohol/drug training projects. These funds, $500,000 for NIDA and $500,000 for NIAAA, were designated within the NIMH budget line item. However, the Administration proposed that clinical training funds be rescinded, and no funds are requested in FY 1987 for clinical training.

Funds are needed in FY 1987 to allow NIAAA to develop a clinical training program, based on the needs assessment supported in FY 1985. It is suggested that $2.0 million ($1.0 million for NIDA and $1.0 million for NIAAA) is an appropriate amount for this purpose and should be designated as a budget line item in the appropriations for these institutes.

I look to the Congress to recognize the importance of continuing a federal commitment in this area. These training activities provide incentives for important private sector activities. The clinical training funds that have been available to NIAAA and NIDA over the years have been modest but I believe both of these institutes have launched programs with these funds which have been highly effective and singled out for praise by the Public Health Service and by health professionals.

Direct Operations

The direct operations funds provide for staff support as well as contracts for prevention activities, research dissemination, policy analysis, consensus development, and technical assistance. These funds were reduced significantly in FY 1986 and the Administration proposes further reductions in FY 1987. In order to absorb the cuts and offset mandatory increases, a reduction of $.6 million will be required in contracts, compounding the shortfall that already exists in FY 1986. A reduction of $.2 million is also required in administrative overhead.

An additional $2.3 million over the Administration's proposed budget of $10.9 million is needed as follows:

-- $.2 million to restore reductions in administrative overhead

-- $1.0 million to restore FY 1986 and FY 1987 contract reductions

-- $.5 million and 5 new positions to keep us with program growth

-- $.6 million to restore postponed contract activities, including activities performed by the Clearinghouse, planned prevention activities, and activities related to the homeless and AIDS

Summary Concerning Recommendations on Appropriations

The Administration's proposed budget for FY 1987 is inadequate to the needs in the alcohol research field. Additional funds are needed as follows:

-- $15.4 million for research to fully meet commitments and allow a moderate level of growth

-- $.5 million for research training to increase the numbver of trainees from 63 to 80

-- $1.0 million to establish a clinical training program in alcohol abuse and alcoholism

-- $2.3 million for direct operations to restore cut in administrative overhead and contracts, provide reasonable expensiuon for contract activities, and provide 5 additional positions to meet increased workload

At the outset of this testimony, I stated my personal interest and experience in substance abuse medical education. In recommending clinical training funds, I praised NIAAA and NIDA for their use of these funds in prior years. Most noteworthy was the Career Teacher Program. Recently, these institutes have taken initiatives in the training of all primary care physicians. A good example of public-private partnership activity was the last national conference (in November 1985) of AMERSA. The conference was sponsored by the Association for Medical Education and Research in Substance Abuse (AMERSA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA). It was co-hosted by the Annenberg Center for Health Sciences and the Betty Ford Treatment Center of The Eisenhower Medical Center in Rancho Mirago, CA. The theme of the conference was "Alcohol, Drugs and Primary Care Physician Education: Issues, Roles, Responsibilities." This theme was chosen because it is widely recognized that medical education has given insufficient attention to alcohol and drug issues, and it is clear that too many practicing physicians do not have the knowledge or skills to diagnose, intervene, and adequately treat their patients with alcohol and drug problems. Although every practicing physician will encounter patients with substance abuse problems, physicians in family medicine, internal medicine, pediatrics and psychiatry are in a good position to have major impact on the problem. Early stage patient presentation is often non-specific and is thus likely to be seen first by the primary practitioner. Initial complaints may also be mainly social and behavioral in nature or initiated by other members of the family, again bringing the patient into contact with the family physician first.

The conference challanged its invitees of informed physicians, medical educators, primary care specialists, and other vitally involved in medical education to reach a consensus on the essential knowledge and skills required of primary care physicians, and the key implementation steps necessary to secure such as part of medical education. The consensus that was reached is a start towards addressing the problems and needs as the more than one hundred participants saw them.

This consensus is now being refined by several national professional associations so that it will be more applicable to specific primary care disciplines. For the interest of the Committee and its staff I am providing a copy of that consensus statement.

Lastly, I wish to comment on the need for and importance of quality treatment outcome reseearch. The Center For Alcohol Studies At Brown has just completed an analysis of Substance Abuse Treatment in Rhode Island at the request of the state government. We were asked to perform this policy research analysis so health planning (which in Rhode Island includes Certificate of Need requirements) could be responsive to the demonstrated need for treatment as well as the need to make the health care system more efficient and cost effective. The report which I have with me and can provide to the Committee is a example of how a state government and its citizen advisory bodies attempt to do the right thing but are hampered by a lack of knowledge about what treatments work best. Since we have a variety of treatments available in Rhode Island, it was common sense to cost-conscience planners and insurers that the Brown study should recommend a method for matching particular patients to specific treatments. Dr. Richard Longabaugh, the research coordinator of the Brown Center, and an acknowledged expert in treatment outcome research prepared a chapter in this policy research report entitled "Treatment Approaches and Patient-Treatment Matching for Persons with Alcohol Problems". To the frustration of the policy makers, the conclusions of that review chapter were inconclusive.

The Brown Center for Alcohol Studies has responded by setting for the coming year as its highest research priority the development of a research plan to conduct a statewide monitoring study of the treatment outcomes of different clients treated in different settings. We aim to determine the clinical effectiveness, cost effectiveness and cost benefits of different kinds of program settings, (e.g., inpatient vs. outpatient) treatment intensities, and therapies for different kinds of clients. We are involving providers, and fiscal intermediaries, and active collaboration from the State of Rhode Island in the planning of this study.

Our long-term aim is to develop RI as a demonstration laboratory where we can both conduct clinical trials to determine effective intervention under experimental conditions and also to test the impact of these therapies as they are delivered in naturalistic settings. The statewide monitoring will accomplish this aim, as we already have several clinical trials completed or underway. In previous clinical trials we have demonstrated the superior cost effectiveness of partial hospitalization and extended inpatient treatment for the average alcoholic. We have also shown in a clinical trial the superiority of a family social skills training program over a mood management treatment. Our concern with matching client characteristics with treatments has lead us to studies examining the treatment implicatons of the differential reactivity of alcoholics to alcohol and the effectiveness of therapies involving the client's environment compared with treatment focused solely on the client.

These activities reflect the priorities we believe to be most important for treatment research the next decade. We believe that clinical trials need to be complimented with naturalistic client treatment placement studies which attempt to maximize client-treatment matching. In order for us to proceed with a sizeable client-treatment matching study, as it will be a large scale investigation, we will be seeking federal support to assist us in conducting the research. Not only will we need to achieve a high priority score in the peer review process, but also the funds will need to be available. This Committee is already aware and supportive of the need for the kind of research that I am describing. The Committee should also recognize that this type of research is costly. A large scale project of the sort described here takes 3-5 years to conduct and has direct costs in the 3-5 million dollar range.

In closing, I thank the Committee for the privilege of appearing before you again.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

DR. JOSEPH PALOMBI, CHAIRPERSON, THE NATIONAL CONSORTIUM FOR CHILD MENTAL HEALTH SERVICES

Mr. NATCHER. Our next witness is Dr. Joseph Palombi. Come around, Doctor.

Mr. STOKES.[presiding] Dr. Palombi, you may proceed in any way you like.

Dr. PALOMBI. Thank you, Mr. Chairman.

The National Consortium for Child Mental Health Services appreciates this opportunity to testify before the Subcommittee on Labor, Health and Human Services, and Education. The issue of mental health services for all Americans has gained attention in recent years as a subject for government study and legislation.

We have seen consideration of the Community Mental Health Center Act, the Mental Health Systems Act, the just completed work on protection and advocacy for people with mental illnesses, and we have the pending bills supporting group homes and new certification methods.

Congress has shown firm support for children's mental health services, especially in initiating the Child and Adolescent Service System Program in 1984 and the Consortium members thank you for that.

I am here today to testify about those special mental health needs of children and adolescents. I am Dr. Joseph Palombi, current Chairperson of the National Consortium for Child Mental Health Services. The Consortium was formed in 1971 to inform and promote understanding about the emotional disturbances of children under age 18, and the special services they require.

The Consortium has 19 member organizations, which are listed at the end of this testimony. All of the members are national, consumer, professional and provider organizations. We meet quarterly to review the state of mental health services for children and to act on activities and issues that need unity and national information strategies to assist their adoption.

We appreciate the subcommittee's support given to specific Federal programs for mental health services for children and adolescents. We urge your continued support for the existing programs within the Alcohol, Drug Abuse and Mental Health Administration, with its National Institutes of Mental Health, Alcohol Abuse and Alcoholism, and Drug Abuse; the National Institute of Child Health and Human Development; and for the Department of Education's Office of Special Education.

The National Consortium for Child Mental Health Services recommends the following funding levels for programs with special support for child mental health services:

For the NIMH Child and Adolescent Service System Program, $6,200,000, from a recommended $20,000,000 for the Community Support Program.

For the Alcohol, Drug Abuse and Mental Health Block Grant, $576,000,000.

For the NIMH clinical training program at the National Institute of Mental Health, $26,000,000, with report language specifying the underserved population of children and adolescents and directing clinical training funds to be used for mental health specialists who care for children and adolescents.

For the NIMH research training program, $31,300,000; and for the NIMH research programs, $272,000,000, again with report language noting the special research needs of children and adolescents, such as these areas singled out by the Institute of Medicine:

One, developmental disorders of infancy; two, hyperkinetic behavioral and attention deficit disorders; and, three, psychotic disorders in children.

Each of these recommendations is in response to the reported 7 to 12,000,000 children in this country suffering with an emotional disturbance. Estimates put the seriously, chronically mentally ill at 3,000,000, with only one-third of them receiving appropriate services.

We can estimate that 10 percent of the Nation's children suffer some form of depression before age 12, and yet depression in children is still largely unrecognized and misunderstood. The 1,200,000 reported cases of child abuse, including sexual abuse, contribute to the numbers of emotional disorders in children and adolescents.

Adolescent admissions to mental health facilities have increased more than 300 percent over the past five years. The influencing factors contributing to the increased need for services show no sign of diminishing: Drug abuse, teenaged pregnancies, economic and society pressures, and unstable family life can result in the need for a continuum of services available to children and adolescents whenever they come in contact with a Federal, State or local agency.

The Education for All Handicapped Children's Act, the ADAMHA Block Grant, Medicaid with its Early, Periodic Screening, Diagnosis and Treatment Program, nutrition programs, and the block grant for child and maternal health all contribute greatly to children's mental health care, but the vast majority of children in need remain unserved, even by programs that should be within their reach.

Too often, there is not the coordination of systems needed to respond when an emotional disturbance threatened to retard development in children and adolescents. For adults, the onset of a mental health problem does not mean the loss of critical months or years of normal growth and development.

For children, the loss of time from their family, friends, school and normal experiences can mean a lifetime of catching up or permanent setback.

It is for this reason the Consortium focuses its support for fiscal year 1987 funding on the Child and Adolescent Service System Program. We ask that the subcommittee again overrule the President's budget request for zero funding and appropriate the Community Support Program at $20,000,000, with $6,200,000 specified for the Child and Adolescent Service System Program.

This program, known as CASSP, was initiated in 1984, when this subcommittee and Congress agreed to an appropriation of

$1,500,000 to improve State service delivery systems for severely emotionally disturbed children and adolescents.

State agencies, even when recognizing the small amount that had been appropriated for nationwide competitive bidding, responded overwhelmingly. 44 applications were received, and 10 grants of $150,000 were awarded.

In 1985, another 12 applications were approved with the $3,900,000 fiscal year 1986 appropriation. Post-sequestration appropriations for fiscal year 1986 provided $4,700,000 to fund continuations, technical assistance and a few new grants.

A total of 24 States are now participating, each according to its own plan design, in the CASSP program. A small portion, $900,000, of the appropriation has gone to providing technical assistance.

The National Consortium for Child Mental Health Services has supported this initiative since its beginning. Members have followed the appropriation process, the applications, the technical assistance, the implementation of the individual programs and the early evaluations.

Every member of the Consortium is in agreement that this is the ideal Federal program; one that combines comparatively modest funding with a high degree of need for a particular service, and results in States being encouraged to create a system best suited to their needs.

The results of this cooperative method for helping children and adolescents receive appropriate mental health care are very encouraging. There is evidence that emotionally disturbed children are receiving more and better services in those States that have been funded; that they are not as liable to "fall through the cracks" or through the "safety net."

The Consortium is recommending that for the fourth year of funding, CASSP receive $6,200,000 from a $20,000,000 Community Support Program appropriation.

The resulting grants from this amount would mean approximately 10 more States could begin work on coordinating a full range of services for children and adolescents in serious need; the technical assistance program moves forward to support all of the State programs; and that all of those involved, the Federal and State agencies, are compelled to, one, identify service gaps and barriers; two, develop service options that do not exist; and three, develop mechanisms for overcoming barriers by changing State regulations, legislation and funding patterns that could hamper provision of the new services.

And, in looking to the future, it means that once a State has developed a comprehensive system on the State level, CASSP promotes the translation of these systems to the community level.

There is a plan in place that moves from cooperation at the Federal to the State and local level. This policy of cooperation has been recommended by almost every Federal commission, whether it is for education, health or mental health. No single level of government provides all of the services, nor is one standard of service provision demanded.

Thank you, Mr. Chairman. I will submit the rest of my testimony to the record.

Mr. Stokes. Thank you, Doctor.

[The statement of Dr. Palombi follows:]

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TESTIMONY OF THE
NATIONAL CONSORTIUM FOR CHILD MENTAL HEALTH SERVICES

ON

FY 1987 APPROPRIATIONS FOR FEDERAL PROGRAMS AFFECTING CHILD MENTAL HEALTH
NATIONAL INSTITUTE OF MENTAL HEALTH

Presented to the

Subcommittee on Labor, Health and Human Services, and Education
Committee on Appropriations
U.S. House of Representatives

Presented by
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2:50 p.m.
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Testimony Regarding:

Department of Health and Human Services

Public Health Service

Child and Adolescent Service System Program

The National Consortium for Child Mental Health Services appreciates this opportunity to testify before the Subcommittee on Labor, Health and Human Services, and Education. The issue of mental health services for all Americans has gained attention in recent years as a subject for government study and legislation. We have seen consideration of the Community Mental Health Center Act, the Mental Health Systems Act, the just completed work on protection and advocacy for people with mental illnesses, and we have the pending bills supporting group homes and new certification methods. Congress has shown firm support for children's mental health services, especially in initiating the Child and Adolescent Service System Program in 1984 and the Consortium members thank you for that. I am here today to testify about those special mental health needs of children and adolescents.

I am Dr. Joseph Palombi, current chairperson of the National Consortium for Child Mental Health Services. The Consortium was formed in 1971 to inform and promote understanding about the emotional disturbances of children under age 18, and the special services they require. The Consortium has 19 member organizations, which are listed at the end of this testimony. All of the members are national, consumer, professional and provider organizations. We meet quarterly to review the state of mental health services for children and to act on activities and issues that need unity and national information strategies to assist their adoption.

We appreciate the Subcommittee's support given to specific federal programs for mental health services for children and adolescents. We urge your continued support for the existing programs within the Alcohol, Drug Abuse and Mental Health

Administration, with its National Institutes of Mental Health, Alcohol Abuse and Alcholism, and Drug Abuse; the National Institute of Child Health and Human Development; and for the Department of Education's Office of Special Education.

RECOMMENDATIONS

The National Consortium for Child Mental Health Services recommends the following funding levels for programs with special support for child mental health services:

- For the NIMH Child and Adolescent Service System Program $6.2 million, from a recommended $20 million for the Community Support Program;
- For the Alcohol, Drug Abuse and Mental Health Block Grant, $576 million;
- For the NIMH clinical training program at the National Institute of Mental Health, $26 million, with report language specifying the underserved population of children and adolescents and directing clinical training funds to be used for mental health specialists who care for children and adolescents;
- For the NIMH research training program, $31.3 million, and
- For the NIMH research programs, $272 million, again, with report language noting the special research needs of children and adolescents, such as these areas singled out by the Institute of Medicine: 1. developmental disorders of infancy, 2. hyperkinetic behavioral and attention deficit disorders, and 3. psychotic disorders in children.

Each of these recommendations is in response to the reported 7 to 12 million children in this country suffering with an emotional disturbance. Estimates put the seriously, chronically mentally ill at three million, with only one-third of them receiving appropriate services. We can estimate that 10 percent of the nation's children suffer some form of depression before age 12, and yet depression in children is still largely unrecognized and misunderstood. The 1.2 million reported cases of child abuse, including sexual abuse, contribute to the numbers of emotional disorders in children and adolescents.

Adolescent admissions to mental health facilities have increased more than three hundred percent over the past five years. The influences contributing to the increased need for services show no sign of diminishing — drug abuse, teen-aged pregnancies, economic and societal pressures, and unstable family life, can result in the need for a continuum of services available to children and adolescents whenever they come in contact with a federal, state or local agency.

The Education for All Handicapped Children's Act, the ADAMHA Block Grant, Medicaid with its Early, Periodic Screening, Diagnosis and Treatment Program, nutrition programs, and the block grant for child and maternal health all contribute greatly to children's mental health care, but the vast majority of children in need remain unserved, even by programs that should be within their reach.

Too often there is not the coordination of systems needed to respond when an emotional disturbance threatens to retard development in children and adolescents. For adults, the onset of a mental health problem does not mean the loss of critical months or years of normal growth and development. For children, the loss of time from their family, friends, school and normal experiences can mean a lifetime of catching up or permanent setback.

It is for this reason, the Consortium focuses its support for Fiscal Year 1987 funding on the Child and Adolescent Service System Program. We ask that the Subcommittee again overrule the President's budget request for zero funding and appropriate the Community Support Program at $20 million, with $6.2 million specified for the Child and Adolescent Service System Program.

CHILD AND ADOLESCENT SERVICE SYSTEM PROGRAM

This program, known as CASSP, was initiated in 1984, when this Subcommittee and Congress agreed to an appropriation of $1.5 million to improve state service delivery systems for severely, emotionally disturbed children and adolescents. State agencies, even when recognizing the small amount that had been appropriated for nationwide competitive bidding, responded overwhelmingly. Forty-four applications were received, and 10 grants of $150,000 were awarded. In 1985, another twelve applications were approved with the $3.9 million FY 1986 appropriation. Post-sequestration appropriations for FY 1986 provided $4.7 million to fund continuations, technical assistance and a few new grants. A total of 24 states are now participating — each according to its own plan design — in the CASSP program. A small portion, $900,000, of the appropriation has gone to providing technical assistance.

The National Consortium for Child Mental Health Services has supported this initiative since its beginning. Members have followed the appropriation process, the applications, the technical assistance, the implementation of the individual programs and the early evaluations. Every member of the Consortium is in agreement that this is the ideal federal program: one that combines comparatively modest funding with a high degree of need for a particular service, and results in states being encouraged to create a system best suited to their needs.

The results of this cooperative method for helping children and adolescents receive appropriate mental health care are very encouraging. There is evidence that emotionally disturbed children are receiving more and better services in those states that have been funded; that they are not as liable to "fall through the cracks" or through the "safety net." The Consortium is recommending that for the fourth year of funding, CASSP receive $6.2 million from a $20 million Community Support Program appropriation.

The resulting grants from this amount would mean:

- approximately 10 more states could begin work on coordinating a full range of services for children and adolescents in serious need,
- the technical assistance program moves forward to support all of the state programs, and
- that all of those involved — the federal and state agencies — are compelled to 1. identify service gaps and barriers, 2. develop service options that do not exist, and 3. develop mechanisms for overcoming barriers by changing state regulations, legislation and funding patterns that could hamper provision of the new services.

And, in looking to the future, it means that once a state has developed a comprehensive system on the state level, CASSP promotes the translation of these systems to the community level. There is a plan in place that moves from cooperation at the federal to the state and local level. This policy of cooperation has been recommended by almost every federal commission, whether it is for education, health or mental health. No single level of government provides all of the services, nor is one standard of service provision demanded.

The Consortium recently heard from the Ohio CASSP director, who reported that the original $150,000 from the federal appropriation has been supplemented by the state to ensure continuation of the program and cooperation by the agencies. The state plan brings together the mental health agency, the human service (welfare) agency, youth services (juvenile justice), the education department, the health department, and the agency handling services for the mentally retarded and developmentally disabled. With these six agencies being brought together, interagency agreements on comprehensive services for children are more easily developed and carried out. Ohio is one of the few states that does individual case reviews to ensure that the child in question is receiving the services available. There are now local coordinating bodies at the county level for "multi-need" children, and resources are being used more effectively, which means freeing money for other new programs. Instead of four different diagnostic evaluations being required for one child, one evalution is done and the results shared with the other agencies.

Ohio is only one of the 22 states receiving funding through the CASSP program. The National Consortium for Child Mental Health Services urges this Subcommittee to support the Community Support Program and the Child and Adolescent Service System Program appropriation in order to fund all of the states applying for assistance. No child should go without mental health services. It can mean a lifetime of suffering. With federal, state and local cooperation no child has to go without help.

Thank you again for this opportunity to discuss one of the federal programs supported by the National Consortium for Child Mental Health Services. I will submit the rest of the testimony to the record and will answer any questions that you have at this time.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH (ADM) BLOCK GRANT

The Consortium recommends appropriations of $576 million in FY 1987 for the ADM Block Grant, which is the foundation of funding for low-cost community mental health services for children and their families.

In the 1985 reauthorization of the ADM Block Grant, Congress addressed the needs of underserved populations by specifically targeting funds for new and expanded services to priority groups, including a 10 percent setaside to be used for seriously emotionally disturbed children and adolescents. This year, Congress should reinforce the existence of underserved populations and the importance of designating setaside funds for serving them. Prior to implementation of the ADM Block Grant in 1981, alcohol, drug abuse, and mental health programs were categorically funded at a level of $638 million. In FY 1986, the current funding level is $490 million — a 23 percent reduction from FY 1981. If inflation is taken into account, the actual reduction of funding reaches over 35 percent in real dollars. ADM Block Grant funds must be increased in order to address the unmet needs of seriously emotionally disturbed children without reducing services to other populations. Adoption of the full FY 1987 authorization level of $576 million would signal a strong continuing federal commitment to those persons suffering from mental illness, including seriously emotionally disturbed children and youth, and would help prevent the need for more expensive hospitalization in later life.

RESEARCH AND RESEARCH TRAINING

The Consortium recommends $303.3 million in FY 1987 for NIMH research and research training programs to improve, prevent, and treat mental illness, rehabilitate affected individuals, and promote mental health.

According to a recent study by the Institute of Medicine, mental illness and substance abuse affect some 30 to 45 million people and cost $20 billion each year in direct health care expenditures. Costs are particularly high for severely disturbed children, who could be affected by mental illness throughout their lifetime. The IOM study points out that substantial breakthroughs in understanding and treating major mental disorders are likely in the foreseeable future. Given the extremely high promise in the field of mental health research and the potential for health care cost savings resulting from such research, particularly for children, it is time for a major expansion of the NIMH research capacity.

CLINICAL TRAINING

The Consortium recommends that the NIMH clinical training program be funded at $26 million in FY 1987, which would assure continuation support and modest new growth.

While the Administration proposes termination of this program, clinical training remains an important component for training professional mental health clinicians of all disciplines and providing specialty training in particular skills. Given the shortage of mental health services for children and other underserved groups, it is essential to provide mental health clinicians with the necessary skills to effectively treat these populations, such as children, with their unique needs.

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

The Consortium recommends $377 million for NICHD for FY 1987, a 17% increase over the FY'1986 level.

The National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, is charged with ensuring through research the birth of healthy and wanted babies, and the opportunity for each infant to reach adulthood unimpaired by physical or mental handicap and to achieve his or her full potential. Research supported by NICHD over the years has furthered our understanding of both normal and abnormal development which, in turn, has enabled us to prevent developmental delays and disorders and treat developmental problems more effectively. Of particular interest to the Consortium is the NICHD Center for Research for Mothers and Children, which includes the Human Learning and Behavior Branch and the Mental Retardation and Developmental Disabilities Branch. Both of these Branches support research to examine the critical interactions among biological, psychological, social, and environmental factors which determine the course of human development.

MATERNAL AND CHILD HEALTH BLOCK GRANT

The Consortium recommends that the committee appropriate $600 million for the Maternal and Child Health Block Grant and support efforts to raise the authorization ceiling this year.

This grant to states, designed to provide health care to mothers, infants, children, and adolescents in poverty or otherwise at risk, reaches only a fraction of those who need services. The health services provided have a strong preventive thrust, and a number of studies have found them to be highly successful in reducing infant mortality, mental retardation, and other developmentally disabling conditions. The Administration's proposal to freeze funding at the pre-sequestration level would in fact mean a 7% cut in services, given the rate of medical inflation. The Consortium recommends increased funding to maintain current service levels and prevent more costly long-term health problems.

Members of the National Consortium for Child Mental Health Services:

American Academy of Child Psychiatry
American Academy of Pediatrics
American Association of Children's Residential Centers
American Association of Psychiatric Services for Children
American Medical Association
American Orthopsychiatric Association
American Psychiatric Association
American Psychological Association
American Society for Adolescent Psychiatry
Child Welfare League of America
Children's Defense Fund
National Association of School Psychologists
National Association of State Mental Health Program Directors
National Center for Clinical Infant Programs
National Congress of Parents and Teachers
National Council of Community Mental Health Centers
National Mental Health Association
Psychiatric Adolescent & Child Treatment & Education Coalition
Society of Professors of Child Psychiatry

THURSDAY, MAY 1, 1986.

REFUGEE RESETTLEMENT PROGRAMS

WITNESSES

HON. BRUCE F. VENTO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

JANE KRETZMANN, STATE OF MINNESOTA STATE REFUGEE COORDINATOR

Mr. STOKES. We now recognize one of our colleagues, Mr. Bruce Vento. You have Jane Kretzmann with you.

Mr. VENTO. Mr. Chairman and members of the subcommittee, I am pleased to have the privilege of being here with you today to introduce Jane Kretzmann. Jane is the State Refugee Coordinator for the State of Minnesota's Department of Human Services.

Jane has served in her present capacity as Refugee Coordinator since 1978, when she was appointed by Governor Rudy Perpich. She was subsequently retained in this position under the Administration of Governor Al Quie from 1979 to 1983.

In 1983, Governor Perpich again reappointed Jane to head up our State's refugee program. Jane has considerable experience in our State government and has also served with various refugee volunteer agencies in Minnesota.

Our State has become home to a sizable refugee community. The Fourth Congressional District of Ramsey County, which I represent, contains one of the largest communities of Hmong refugees of any District in the Nation. We are proud of the many contributions which our refugees have made to enriching the culture and heritage of Minnesota.

I know that Jane shares my concern that our Federal Government honor its responsibility and commitments to our State and local governments which must meet the resettlement needs of our refugees.

Mr. Stokes, the high school I graduated from, it is the same high school that our former Senator Wendell Anderson graduated from, and our Supreme Court Justice, Mr. Burger, graduated from.

We are all in the Hall of Fame there, hanging up in the library. Last year, that high school, and it is still a middle-income high school, newly built in the sixties, but still retains the proud name, half the top 10 students in that high school were Indochinese.

It has 20-plus percent Indochinese students in my District, St. Paul, and a high percentage of the public housing is given over to the Indochinese, and through our various Federal programs, it gives you an idea of the type of impact.

Jane shares my concern that our Federal Government continue to honor its responsibilities to meet the resettlement needs of our refugees.

In Minnesota, the Lutheran and Catholic Social Services, and other public or private groups have done an outstanding job of helping us in this assistance, but it is a monumental task, and we need the continued support of the Congress and this Administration, to do a credible job to meet these needs.

We are doing it there. For some of these populations, especially for the Hmong, who do not have the educational background, it is a difficult task. If we continue to do the job there, we can get the kids trained, and they are outstanding students.

Jane could tell you what type of research she has to have in the programs, and some of the problems we have with proposals that have been made by the Administration.

I know you will do the right thing by us, so we continue to provide the services. With that, I introduce Jane Kretzmann, if I haven't stolen all the thunder.

Mr. STOKES. It is going to be tough for her to follow that. You have done an excellent job of introducing her, and given us some interesting information, background information.

Mrs. Kretzmann, we are pleased to recognize you.

Ms. KRETZMANN. I represent a State which has had a long and active involvement in the resettlement of refugees, and which continues to devote substantial resources, both public and private, to this population.

Our State's voluntary resettlement agencies and sponsors have done a commendable job in the past decade, maintaining local staff despite dwindling resources and continuing to sponsor additional families.

Minnesotans have witnessed tremendous growth in the Southeast Asian refugee population since 1980, jumping from 8,000 to nearly 30,000. Today, less than half of the refugee population relies on some form of public assistance.

Of the approximately 13,000 individuals receiving welfare, two-thirds have been in the country more than 36 months (time expired), and are now State and county responsibilities.

Federal support for the remaining one-third time-eligible population, over 4,000 individuals, is now threatened by the Federal budget for fiscal year 1987.

That threat equates to $4,000,000 in cash, plus medical assistance reimbursement; over 500,000 in K-12 education assistance; over 500,000 in social services for adults; and over $1,000,000 in targeted assistance for employment services in Ramsey and Hennepin Counties, our two most impacted areas.

Since 1982, Minnesota has received approximately 1,800 primary refugee migrants to the State each year. In addition, our data has identified another 30 to 40 percent of our public assistance and social service clientele who were originally resettled in other States.

Minnesota has become one of the "promised lands" for secondary migration of refugees. In spite of greater heterogeneity in the composition of refugee arrivals at the national level, Minnesota has maintained the same ethnic distribution over time.

We are home to nearly 10,500 Hmong, 7,600 Vietnamese, 6,100 Cambodians, 4,500 Laotians and 1,200 other non-Southeast Asian ethnic groups.

Just as the refugees describe the Minnesota weather as a climate of extremes, ours is a program and population of enormous contrasts:

One, this spring, one valedictorian, and 10 of the top 10 students in four St. Paul night schools are Southeast Asian refugees.

Two, of the approximately 13,000 refugees on welfare, over 65 percent are under the age of 17, over 65, or disabled.

Three, most of Minnesota's new jobs are in the service economy. This type of job usually pays $4 per hour or less, and has no health benefits.

Four, refugees must compete for entry level jobs in a shrinking labor market, the result of various economic problems: The farm crisis, the flattening of the computer market, and depression conditions of the Iron Range in northeast Minnesota. In some counties, unemployment exceeds 22 percent, and native-born Minnesotans have become refugees within their own State.

Our purpose today is to describe Minnesota's deep concerns regarding the direction of the refugee program which reflects an apparent reneging of the Federal commitment to States and localities, and which threatens the future capacity of this country to resettle refugees.

The proposed reduction in Federal reimbursement to 18 months would penalize States with significant refugee populations. In addition to the immediate cost, the proposed reduction has other implications when considered with the ORR proposed rule, published in the January 30, 1986 Federal Register.

The rule would limit eligibility for support services to cash and medical reimbursement eligibility. Therefore, time eligibility would be reduced to 18 months for refugees' use of "support services." Most of Minnesota's refugees have needs which go well beyond the three-year limit, notwithstanding the 18-month proposal.

Refugees' needs for social services will exist whether or not there is funding. Family adjustment problems, domestic abuse, problems in communication and cross-cultural understanding in the work place, depression, loss of self-esteem resulting from layoffs, or repeated failures to learn English or get a job, these are examples of the kinds of problems refugees confront every day.

Most of these problems are similar to those of other Americans, except these individuals face the added burden of being a refugee.

States and counties have already directed substantial non-Federal refugee dollars to meet the needs which go beyond current levels of support and Federal program priorities.

The Administration's proposal to reduce the social service appropriation to $45,000,000 would cause further irreparable harm to refugees and exacerbate the barriers to refugees' efforts to become self-sufficient.

The magnitude of the proposed cut in social services would have a significant impact on our State, due to the characteristics of as many as 40 to 60 percent of Minnesota's refugees:

Severely limited English language competency, little or no education in their homeland, inability to read and write in their native language, limited or no prior wage or salaries work history in the U.S.

Large family size often causes extreme disincentives to accepting entry-level employment.

Over age 45 with a combination of language deficiencies and limited or non-applicable prior work experience.

Emotional, psychological or medical impairments which restrict the range of available employment.

However, as the data on time-eligible refugees presented below demonstrates, many of the new arrivals in Minnesota possess the same characteristics as the time-expired population will on welfare. We anticipate this pattern to continue in new arrivals who have experienced greater hardships in the camps.

An assessment of 1985 program data shows the following:

48 percent of all ESL slots were used by refugees who could understand only a limited number of words and phrases, could not write their names without help, and could recognize none or few sight words.

62 percent of the Hmong and 48 percent of the Cambodians enrolled in ESL classes fit the above characteristics.

37 percent of the clients in case management and employment had received five years or less of education in both their homeland and America.

65 percent of all time-eligible refugees on cash assistance in Ramsey County are children. The average grant size is 4.5. 34 percent have children under 6.

51 percent of all time-eligible refugees on cash assistance in Hennepin County are children. The average grant size is 3.1. 20 percent have four or more children.

Hennepin and Ramsey County account for 61 percent of the time-eligible public assistance case load in the State.

16 to 20 percent of adults currently on cash assistance in Ramsey and Hennepin Counties are over 45 years of age.

2,646 adult refugees were seen in special adjustment/mental health projects during 1985. This is an increase of 1,000 persons from one year ago.

38 percent of all new arrivals in the last three years have been Cambodians. The language level of the most recent arrivals is significantly lower than in previous years.

While only 14 percent of the new arrivals have been Hmong, Minnesota is expecting an increased percentage during 1986 as part of a national program to resettle the Hmong out of the Thai refugee camps. This always results in an increased secondary migration for the State.

Minnesota's approach to meeting the needs of this more "difficult to place" population has been the development of a multi-service system approach to address the assimilation and acculturation problems with present self-sufficiency.

The State has emphasized acquisition of employment readiness English skills; early employment for singles and those with small families; identification of secondary and multiple wage-earners in large families; and strengthening a support system to work with the multiple problems which affect the ability to achieve economic independence in Minnesota communities.

The proposal to cut K-12 education assistance is a clear shift of costs, in that refugee children arriving from overseas camps and from homelands whose educational systems have collapsed which still need special services.

These young people enter our school system at a distinct disadvantage. This past year, over half of Minnesota's time-eligible children were enrolled in secondary schools. The presence of "older" children is a direct reversal of earlier refugee arrivals.

Experience shows that beyond the ages of 10 and 12, the acquisition of English is sufficiently slow that "meaningful" high school diplomas are problematic even with Federal aid. Elimination of this support jeopardizes these young people, a natural resource for the future of our country.

To move refugees from entitlement programs to discretionary programs which are easily cut is to refuse refugees' access to mainstream Federal assistance programs, and sets the stage to shift costs to States.

There is recent evidence to support this conclusion. On March 1, States saw their Federal reimbursement reduced from 36 to 31 months through a single administrative action. An all RCA program is an all-discretionary program, most vulnerable to Federal cuts.

In July 1985, of 599 refugee AFDC cases, 48 percent were two-parent, 43 percent single, and 9 percent child only. Over half of that case load would be inappropriate for an all-RCA program, yet would, under the budget proposal, be denied access to an appropriate entitlement program.

Legal residents of the U.S. should be treated equally with American citizens concerning entitlement to financial benefits in the same way they are protected equally under the law.

Minnesota has a general assistance program. To the extent an alternative RCA program fails, refugees would qualify for State and county-funded general assistance programs, without Federal financial participation.

Our State has long been concerned that Federal refugee policies are short-sighted. Stable self-sufficiency has been the goal of our Minnesota program. Minnesota has been heralded for its humane response to refugees.

At the same time, the State has been criticized for its high welfare dependency rate, and its emphasis on English language training. We do not contest that there are many individual refugees who could benefit or even prosper from early employment.

However, as the ORR/DHHS proposed rule indicates, the Federal emphasis denies the need to speak English to get a job, and outlines a single path for early employment. The problem results from the myth of early employment.

We think nothing of preparing our own children for the outside world with a minimum of 13 years of education, yet deny the need of refugees for education. As Susan Forbes of the Refugee Policy Group reports in The Adaptation and Integration of Recent Refugees to the United States, there is a complicated relationship between English language and economic adaptation.

She writes, "It may be that knowledge of English does not have a significant, independent effect on the capacity of a refugee to seek and even find jobs, but that English does affect the capacity to earn sufficient wages to raise the household income above poverty level."

To the uneducated, untrained refugee, the pattern can be recurring unemployment, a revolving-door syndrome in the labor market. States need flexibility to address the unique needs of the refugees and particular local labor markets in order to avoid the creation of a permanent underclass of people.

In our work with other States on the issue of refugee resettlement we have consensus on the need for the following improvements:

First, the Federal-State partnership must be mutually consultative and stable. Southeast Asian refugees live in nearly every State of the Union.

However, 75 percent of the population resides in just 10 States. Only 15 States have Southeast Asian refugee populations in excess of 10,000 persons. The importance is that we are not talking about nationwide impact on the domestic side, although the program itself is tied to our national policies. Funding must be restored to 36 months' reimbursement.

Second, the role of the private sector, specifically the voluntary agencies, needs enhancement and support. We recommend an increased reception and placement grant to accompany the proposal for improved accountability and coordination with the public sector.

Third, the welfare system for refugees must provide incentives for work. We support a reevaluation of the 100-hour rule. The retention of deductions for work expenses and the 30 1/3 income disregard are necessary to maintain comparability with AFDC and Title XIX.

We favor adaptation of mainstream entitlement in order to ensure client protections, and provide Federal guarantee of equal opportunity for persons legally admitted to this country.

Fourth, the Department of Health and Human Services should mandate and fund attention to refugees, both time-eligible and time-expired, who are now enrolled in WIN across the country.

In its administrative role, DHHS can improve the coordination of refugee serves with WIN, for as long as it exists, by providing funding and establishing consistent program standards and reporting requirements between these two programs.

Fifth, we have joined other refugee States in requesting the Office of Refugee Resettlement to withdraw its proposed rule, published in the January 30, 1986 Federal Register, and to appoint a task force to write workable, legal and cost-effective regulations.

Lastly, this is not the time to cut the refugee budget. States and localities are dealing with other cuts in Federal domestic programs. Refugees with special needs, limited educational backgrounds and large families continue to be resettled.

It has been said many times in different ways: The decision to admit refugees is a Federal prerogative. However, it is the responsibility of the Federal Government to meet refugee resettlement costs. To reduce this program by 50 and 100 percent is irresponsible and capricious.

Congress should act carefully to properly diagnose the problems in the refugee program before prescribing a cure. The discussion of a national dependency rate, for example, must take into account the number of actual potentially employable individuals, the economies of the various States, the characteristics of the resident refugee populations, and the comparable public assistance benefits available among the various States.

The substantial changes proposed for the Refugee Resettlement Program run so contrary to the original intent of the Refugee Act of 1980 that Congress should expand its consultation to States concerning the reauthorization.

Congress should establish a national work group of the 10 to 15 largest States on whose shoulders the time-expired refugee costs rest and whose populations resulting from family reunification will continue to grow.

Thank you very much for your time.

[The information follows:]

ADAPTATION AND INTEGRATION OF RECENT REFUGEES TO THE UNITED STATES

RPG REFUGEE POLICY GROUP

ADAPTATION AND INTEGRATION OF RECENT REFUGEES TO THE UNITED STATES

by
Susan S. Forbes

August 1985

ACKNOWLEDGEMENTS

This project began as a conference held at the Wingspread Conference Facility co-sponsored by the Refugee Policy Group, the Office of Refugee Resettlement and the Johnson Foundation. Many of the researchers whose studies are cited herein presented their research findings to their colleagues and policy makers from federal and state government and private agencies. The ensuing discussion was invaluable in setting the stage for this synthesis and analysis of policy implications.

The actual preparation of the report took place under a grant from the Exxon Corporation, whose Program Officer, Jerrold Weitzman, participated in the Wingspread discussion.

Special thanks go to Allan Gall of the Office of Refugee Resettlement who co-organized the Wingspread Conference, commissioned special reports that summarized findings on key research issues, and, at every stage of this project, provided insight, advice and encouragement. Sections of this paper were first prepared under grants from ORR to examine the residency patterns and impact of refugees.

Research assistance was provided by Maria Boza and Joanne Schneider.

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INTRODUCTION

Since the end of World War II, the United States has admitted almost two million refugees for permanent resettlement. Principally from Communist dominated countries, they have come from every continent: Europe (Germany, Poland, Hungary, Soviet Union, Rumania, Czechoslovakia, etc.); Asia (Vietnam, Kampuchea—formerly Cambodia—Laos, China, Indonesia, Korea, Afghanistan, Iran, Iraq, Lebanon, etc.); Africa (Ethiopia, Uganda); and Latin America and the Caribbean (Cuba, Chile, Nicaragua, El Salvador).

As could be anticipated by the variety of national origins, the refugee experience has been anything but homogeneous. Refugees from some nationality groups have been admitted as part of a large movement of people from the same region (for example, more than 700,000 Southeast Asians have entered the United States as refugees); others have come as individuals accompanied by few of their compatriots. Some refugees have joined members of their ethnic group who had already immigrated; others have come as ethnic pioneers. Some refugee movements have occurred rapidly, with most members of a nationality arriving within a short period (for example, Hungarians); others have continued, at least intermittently, for many years (for example, Cubans). Some refugees have arrived with financial resources; many others have not. Some refugees have had high levels of education and training; many others have arrived with few transferable skills and knowledge. Some refugees have spoken English upon arrival; others have not. Some refugees have held senior positions in the government or military of their countries of origin; others have been far from the centers of power and influence. Some refugees have fled because of their political affiliations and involvements; others left because of their racial or ethnic identification, and still others because of their religious beliefs. Some refugees have come with massive humanitarian attention focussed on their flight; others have entered with little or no fanfare.

All these factors influence the reception and ultimate integration of refugees into U.S. society. But there are still other factors which have less to do with the characteristics of the refugees themselves and more to do with the status of this country at the time of their entry. Among these factors are the state of the economy; prevailing attitudes toward foreigners; other legal and illegal immigration, as well as internal migration patterns; availability of services and support structures; public-private and federal, state and local relationships; and public policy regarding refugee admissions and resettlement.

Until 1980, the United States responded to these disparate movements of people through separate legislative and administrative initiatives, such as the Displaced Persons Act of 1948, the Refugee Relief Act of 1953, the Refugee-Escapee Act of 1957, the Hungarian Refugee Program of 1957, the Refugee Fair Share Act of 1960, the Cuban Refugee Program, and the Indochinese Refugee Assistance Program. By the late 1970s, it became clear to policy makers that refugee resettlement in the United States is a permanent reality that is ill served by *ad hoc* legislative responses. Instead, permanent, comprehensive legislation was needed which would establish policies regarding not only the admission of refugees (how many? from where? by what criteria?), but also the assistance provided to them once resettled in the United States.

In drafting the assistance sections of the Refugee Act of 1980 and its subsequent amendments, policy makers faced a difficult challenge: designing legislation that would serve the needs of the current refugee population while providing a framework for admitting and assisting the as-yet unknown refugee groups to follow. The diverse experiences of the past argued for retaining a maximum degree of flexibility, while the reality of the existing refugee program called for resolving certain basic issues: What were the boundaries of federal responsibility for the costs of refugee resettlement? What measures would be adopted to assure that refugees did not pose a threat to the public health and that their health condition did not become a major obstacle to their adjustment in the United States? How would the special needs of refugees be met without creating inequities vis a vis other disadvantaged populations? What placement policies would be adopted to balance the desire of refugees to live in large clusters with family members and others of their ethnicity with the concerns of states and localities about the negative impacts of large concentrations of refugees? What would be the ongoing relationships of the private voluntary agencies responsible for the initial reception and placement of refugees with the state governments responsible for administering public assistance and social service programs for the new arrivals? And, most important, what policies could assure meeting the transitional needs of refugees while encouraging their adaptation and integration into U.S. society?

In drafting legislation, Congress took into account a number of factors:

- the interests and needs of the federal, state and local governments;
- the interests and needs of the resettled refugees;
- the interests and needs of refugee-serving agencies in both the public and private sectors;
- the world refugee situation; and
- U.S. foreign policy commitments and humanitarian responsibilities.

The following provisions emerged from this process: First, the Refugee Act explicitly states that the objective of the assistance program is "effective resettlement" of refugees as rapidly as possible. More specifically, the legislation defined effective resettlement in terms of economic self-sufficiency.

Second, the Refugee Act described the basic roles and relationships of the organizations inside and out of government that were to have primary responsibility for resettlement. It created an Office of Refugee Resettlement in the Department of Health and Human Services, which was charged with responsibility for funding and administering assistance programs for refugees. It also recognized the role of private, non-profit agencies in the reception and placement of refugees in U.S. communities. And the legislation prescribed a role for states, specifying that as a condition for receiving federal funds, they must: submit plans describing how they intend to implement their programs in accordance with the objectives of the Act; and designate individuals responsible for coordinating program activities.

Third, the Refugee Act specified that resources were to be made available for interim cash and medical assistance, employment services, language training programs and other services geared toward attaining the objective of self-sufficiency. Refugees could be assisted on a preferential basis (for example, some eligibility requirements for cash and medical assistance could be waived and special programs could be implemented) if the assistance would encourage self-sufficiency and/or avoid a significant burden on states and localities.

Fourth, the Refugee Act provided for 100 percent federal reimbursement of state costs during the first 36 months a refugee is in the United States. This provision on the one hand established in permanent legislation that the federal government would bear the cost of resettlement, while, on the other, it limited the period during which reimbursement could be made.

Fifth, the Refugee Act instructed the federal government to monitor assistance programs, collect data from states and voluntary agencies, and report to Congress annually on the employment status of refugees, their location within the country, the results of monitoring and data collection, and other summary information.

The existence of a refugee program with its own authorizing legislation and appropriations of funds draws attention to the costs, impacts and effectiveness of the system established to resettle its clients. This raises questions such as: How well have recently resettled refugees fared? Have refugees followed the same patterns of adaptation as other immigrants? To what extent has programmatic assistance aided or impeded the resettlement process? To what extent does this process unfold independent of programmatic assistance? Are the timeframes and expectations referenced in the Refugee Act appropriate?

Prior to 1980, there was little systematic attempt by the government or anyone else to document the experiences of refugees within the context of federal, state or private assistance programs. Federal policy evolved through a "trial and error" process with relatively little information about the needs of specific groups, the effectiveness of programs or the short- or long-term impact of refugees on receiving communities.

In response to this information gap, made more evident with the passage of permanent legislation, the federal government embarked on a major research effort. During the past four years, the federal government has funded over $3.5 million in research and evaluation studies of refugee resettlement. Most of these studies were sponsored by the Office of Refugee Resettlement, but other important projects were initiated by the Bureau for Refugee Programs in the State Department and the Center for Population Research in the National Institute of Child Health and Human Development.

The Refugee Act was passed and has been implemented during a period dominated by the resettlement of Southeast Asian refugees. The experiences in resettling these refugees influenced not only the legislation itself, but—even more—the interpretation and implementation of the law. This is so much the case that assessments of the adaptation of refugees under the Refugee Act must be predominantly an assessment of the Southeast Asian experience. Indeed, most of the recent research and evaluation studies have focussed almost exclusively on the experiences of Indochinese refugees and programs designed to serve their needs. There are few studies of other current arrivals. Nor, for that matter, are there many studies of previous refugee groups that can be used for comparative purposes.

Nevertheless, through recent research on refugee resettlement, we now know more than ever before about the experiences of refugees and the effectiveness of U.S. resettlement programs. Although these studies do not provide definitive answers to the questions posed above, they do enable us to begin the process of documenting and analyzing what it is we know about refugees, what we should expect of them and what we should expect of U.S. policies and programs.

This report, based on a synthesis of available research on refugee integration and adaptation, is divided into three major sections. The first part summarizes information on the extent of refugee economic and social adjustment and analyzes factors that have facilitated and impeded refugee adjustment; the second describes the impact refugees have had on U.S. communities; and the third discusses the policy implications of these research findings.

HOW ARE REFUGEES DOING?

There are many measures of adaptation: the ability to support oneself; the capacity to speak the language of one's new home; understanding cultural values; development of culturally appropriate organizations; and participation in political processes. Of these measures, three have been emphasized in research reports. Because economic self-sufficiency has been the explicit objective of the resettlement program, measures of economic adaptation have received primary research attention, particularly in government-funded projects. Language acquisition has also been studied, since it is seen as a major contributor to economic success, as well as important in and of itself. And, finally, research has focussed on the development of ethnic support structures—termed "mutual assistance associations"—as necessary intermediaries between the refugees and U.S. society.

Economic Adaptation

Few outcomes, if any, are as important in measuring the effectiveness of refugee resettlement as the economic adjustment of the new arrivals. Economic self-sufficiency—measured by labor force participation and employment rates, income level and use of public assistance programs—affects not only the lives of the refugees but also 1) the costs of the resettlement program, 2) the impact of refugees on the U.S. labor market, 3) the impact of refugees on mainstream programs, and, ultimately 4) the receptivity of the United States to the admission of refugees.

Generally, the prospects for refugee economic self-sufficiency are promising in the long-term, but the immediate situation shows low labor force participation, high unemployment, large numbers living below the poverty line, and substantial reliance

TABLE I Labor Force Participation and Employment Rates October 1984

	Labor Force Participants	Employment
Refugees	55.0%	85.0%
U.S. Population	64.0%	93.0%

on public assistance programs. Key to understanding economic adaptation is the employment experience of refugees, since other economic measures (earnings, income, public assistance) vary with the extent to which refugees are in unsubsidized jobs. Therefore, special attention is paid in this analysis of economic adaptation to employment data.

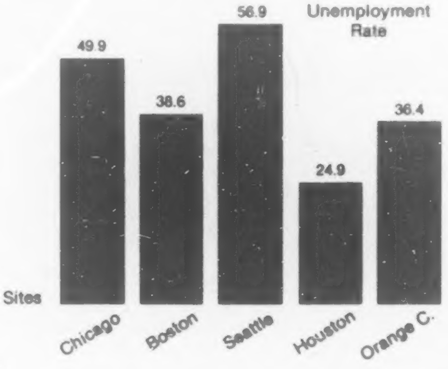
Patterns of Employment

Employment takes place in two stages, both of which have been examined in research reports on refugees. First, newscomers to this country must actively seek work. Second, they must find and accept employment. Labor force participation rates measure the percent of persons over the age of 16 who are either looking for work or actively employed. Employment rates measure the percent of those in the labor force who are actually employed.

Within the general U.S. population, about 65 percent of the working age population is in the labor force at any given time. The most recent national survey on refugee participation in the labor force (October 1984) shows that 55 percent of all Southeast Asian refugees over the age of 16 were employed or actively seeking work (ORR: 1985). Included in this statistic are refugees who entered the United States between 1975 and 1984. Overall, 58.7 percent of male refugees are in the labor force, while 41.3 percent of female refugees have or are seeking work. The comparable figures for the U.S. population are about 76 percent and 53 percent, respectively. About 85.4 percent of those in the labor force were employed, as compared with 93 percent in the overall U.S. population. (See Table I.)

A second survey, the "Southeast Asian Refugee Self-Sufficiency Study" by the Institute for Social Research (ISR: 1985), examined employment patterns among more recently arrived refugees who lived in five sites: Houston, Texas; Orange County, California; Boston, Massachusetts; Seattle, Washington and Chicago,

TABLE II Employment by Site (all adults)



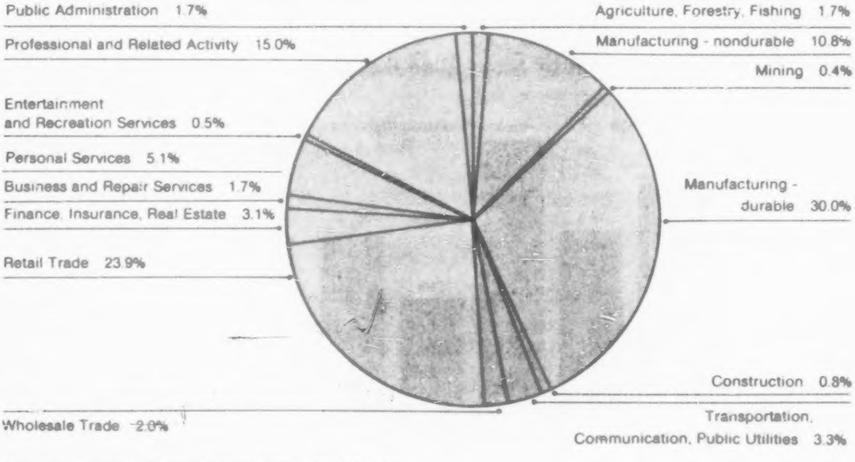
Source: Institute for Social Research, "Southeast Asian Refugee Self-Sufficiency Study. Final Report," 1985.

Illinois. Data collection took place in 1982 among refugees who had arrived in the United States since 1978. Unemployment rates were found to be relatively high in all sites, ranging from 24.9 percent in Houston to 56.9 percent in Seattle. (See Table II.) These rates are higher than overall U.S. unemployment (10.1 percent), black (19.8 percent), Hispanic (14.8 percent), or, even, teenage (23.6 percent) rates. The unemployment rate for refugee men in the labor force was found to be higher (44 percent) than that of women (39 percent). The authors pointed out, though, that many women defined themselves as housewives when outside work was not available to them. As a result, they were not included in the labor force even if they would take jobs if offered.

Type of Employment

The research gives valuable information on the type of employment that refugees have found. This information is useful in assessing whether initial employment is likely to lead to long-term self-sufficiency. In "Labor Force Participation and Employment of Southeast Asian Refugees in the United States," Robert Bach found that over 40 percent of the refugees worked in manufacturing, with almost 25 percent working in retail trade (Bach: 1984). Professionals accounted for 15 percent of the employed. (See Table III.) More specifically, four occupational categories employed the vast majority of the refugees: technical, sales and administrative support (24.4 percent), service (21.9 percent), precision production, craft and repair

TABLE III Sector of Employment: All Employed Individuals 16 Years of Age or Over, 1983*



Source: Robert L. Bach, "Labor Force Participation and Employment of Southeast Asian Refugees in the United States," 1984.

*All percentages are weighted by household size.

(21.4 percent) and operators and fabricators (19.3 percent). Within these occupations, refugees tend to hold low-skilled positions. More than one-fourth of those in the service sector are janitors and cleaners, with another 40+ percent working in food preparation and distribution (cooks, kitchen workers, waiters and waitresses and their assistants). Another large percentage of refugees work in the electronics industry, generally in unskilled support positions.

ISR reports similar findings regarding jobs held by refugees who have arrived since 1978. Almost 65 percent of this sample are employed as operatives or in service jobs. Examining the socio-economic status of the jobs held by refugees, ISR concludes that 70 percent hold low-status jobs while only 10 percent have high status ones. Most of the refugees tend to be employed in peripheral jobs in what is often referred to as the secondary labor market.

ISR examined the benefits available to employed members. The majority (75 percent) of those employed full-time had benefits, but only a small proportion of the part-time workers (21 percent) did. Among all workers, 57 percent had health insurance, the most prevalent benefit followed by paid vacations (52 percent). About one-fourth received dental insurance and retirement pensions. Refugees working in the secondary labor market were less likely to be receiving any of these benefits. For example, 45 percent of those in jobs in the secondary labor market received health benefits, compared with 71 percent in core sector jobs.

There is some impressionistic data that refugees may be moving into the underground, cash economy. In "The 1975 Refugees: Their First Five Years in America," Baker and North traced the employment rates and Social Security earnings of refugees who arrived in 1975 (Baker and North: 1984). They found that self-declared employment rates among men increased over time, while reported Social Security income decreased. Not able to find any other explanation for this phenomenon, they hypothesize that some refugees who had previously been employed in jobs that paid into the Social Security system were now in jobs that paid "under the counter."

For many refugees, their initial jobs reflect a decline in socio-economic status. Among refugees who were professionals in Southeast Asia, only 10 percent found professional employment in the United States, according to ISR's study. Most of those who did find jobs worked as operatives or in service jobs, just as did their less educated compatriots.

The pattern of occupational mobility revealed by recent research on refugees is similar to that found in research on immigrants. Many researchers document that immigrants coming from higher socio-economic status in their countries of origin initially take jobs that are lower in status; but with time, their status increases until it reaches or surpasses former levels.

Since this process unfolds over time, it is too soon to tell if Southeast Asian refugees will begin the upward climb or if they will be able to regain their former socio-economic level. The situation of refugees, at least during their initial time in the United States, is not the same as for other immigrants because of their special eligibility for a range of public assistance programs. Also, they generally come with less capital and they have not had the opportunity to plan their move to this country. In "An Analysis of the Economic Progress and Impact of Immigrants" Barry Chiswick, using data from the 1970 Census, found that immigrants who migrate for political reasons—in this case, refugees from Cuba—take longer to close the gap in earnings than do those who migrate for economic reasons (Chiswick: 1980).

TABLE IV Current Employment Status of Southeast Asian Refugees

Year of	Labor Force Participation				Unemployment			
	1981	1982	1983	1984	1981	1982	1983	1984
1984	—	—	—	30.0%	—	—	—	41.0%
1983	—	—	20.7%	41.6%	—	—	55.0%	35.6%
1982	—	25.2%	40.9%	45.4%	—	62.5%	30.4%	12.5%
1981	22.8%	41.5%	46.5%	51.4%	45.2%	40.7%	16.8%	16.4%
1980	52.8%	51.3%	55.3%	54.5%	27.1%	32.1%	21.1%	11.6%
1979	49.2%	60.2%	60.5%	60.1%	8.1%	19.3%	17.6%	9.8%
1978	46.8%	67.6%	68.2%	66.2%	5.0%	19.0%	19.7%	2.6%
1976-7	70.7%	74.3%	79.5%	76.1%	3.5%	9.4%	17.2%	4.6%
1975	76.0%	72.1%	69.7%	67.3%	6.4%	12.7%	12.1%	6.3%
U.S. Rates*	64.0%	64.1%	64.1%	64.6%	7.5%	9.9%	8.4%	7.0%

*October unadjusted figures from the Bureau of Labor Statistics, Department of Labor.

**Proportion of original sample of 2,700 successfully located and interviewed, by year of entry. The total number interviewed, 1,244, . . .

Factors Influencing Refugee Employment

Patterns of labor force participation and employment can be explained by a variety of factors, including the demographics of the refugee population (that is, gender and age); their length of time in the United States; background characteristics; household size and composition; public assistance policies and practices; service utilization; and the general economy.

Demographic Factors: Labor force participation varies by age, with refugee patterns comparable to U.S. ones. In the U.S. population generally, labor force participation is low in the 16 to 24 age bracket; these young people are likely to be involved in educational and training programs. The rate is much higher for those between 25 and 55, after which it declines. Refugee labor force rates show this same general pattern.

Length of Time in the United States: The percent of refugees in the labor force and employed differs markedly by length of time in the United States. As Table IV indicates, 67.3 percent of those who had arrived in 1975 were in the labor force in 1984, a higher rate than the U.S. average. On the other hand, the more recent arrivals showed lower participation rates; only 30.0 percent of the 1984 arrivals and 41.6 percent of the 1983 arrivals were in the labor force as of October 1984. As with labor force participation, employment increases with time in the country. According to the 1984 survey, the unemployment rate for refugees who arrived in 1975 was 6.3

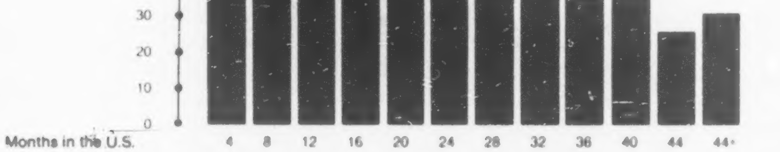
percent, whereas it was 35.6 percent for those who arrived in 1983 and 41 percent for the 1984 arrivals.

As shown in Table V, ISR found that 86 percent of those in the United States for four months or less were unemployed, as compared with 75 percent of those here between 9 and 12 months, 52 percent of those here between 21 and 24 months, and 35 percent for those here between 33 and 36 months. For those here more than 36 months, the unemployment rate was between 25 and 36 percent. It should be noted that the latter survey took place during a period of very high unemployment generally, and that the refugee rates, as discussed below, were obviously affected by the overall recession.

Another change over time is the proportion of households with one or more employed persons. (See Table VI.) Over 80 percent of the households with members in the United States for less than four months have no employed member; about 10 percent have one employed member and less than 5 percent have two employed members. But by the time refugees have been in the United States for more than three years, the proportions have shifted significantly. At that point, only about 20 percent of the households have no employed member; 30 percent have one employed member; and about 50 percent have two or more employed.

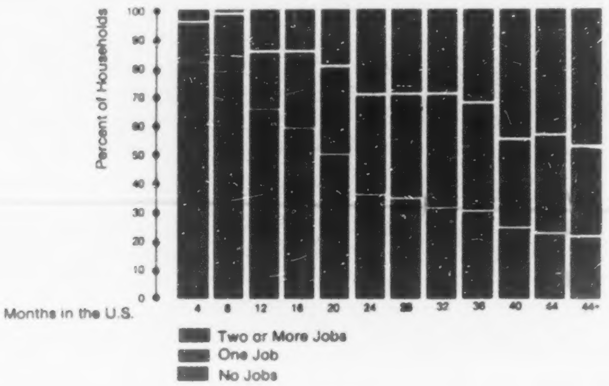
Background Characteristics: A refugee's experiences prior to entering the United States have a profound effect on later adjustment. *Education* in the refugees' countries of origin is among the most important predictors of labor force participation, after controlling for all other factors (e.g., language proficiency, age, gender, length of time in the United States). Bach found that "each additional year of education *before arrival* . . . gives the more educated a 3 percentage point advantage over the lesser trained (his emphasis)." Bach argues that those who have

TABLE V　Unemployment Rate By Time in the U.S.



Source: Institute for Social Research, "Southeast Asian Refugee Self-Sufficiency Study. Final Report," 1985.

TABLE VI Number Employed Per Household by Months in the U.S.



Source: Institute for Social Research, "Southeast Asian Refugee Self-Sufficiency Study Final Report," 1985.

had the social and economic standing to have obtained higher education are in a better position to enter the U.S. labor market. Further, higher education provides knowledge and skills that are transferable from one society to another, aiding job searches and success in getting a job.

The influence of ***language*** is less clearly defined. Most studies, looking at the simple relationship between English language proficiency and labor force participation, have emphasized the importance of language skills. The 1983 survey of Southeast Asian refugees found that labor force participation among those who spoke English well or fluently was over 60 precent, whereas it was only 25 percent for those who did not speak English at all. This finding does not bode well for early employment for refugees, since less than 10 percent of the Southeast Asians who arrive here have a fluent command of English.

Whether it is language itself or other factors that affect employment is hard to gauge, however. The likelihood that a refugee knows English prior to arrival is affected by other factors that are themselves influential in predicting employment: previous education, previous exposure to English speakers, and year of entry (those who came in 1975 were more likely to speak English on arrival than were late migrants). Similarly, the likelihood that a refugee will increase his or her understanding of English is related to other considerations, such as enrollment in a language training program. Bach questions the importance of English proficiency when it is removed from these other factors. For example, controlling for year of entry—that is, looking at refugees who arrived within the same year—English proficiency on arrival loses its predictive value. It appears that refugees arriving in certain years (most notably 1975) are more likely to have entered the labor force *whether or not they know English* than are those who arrived in other years.*

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*As discussed above, other measures of economic adaptation, particularly income, appear to be more significantly related to English proficiency than is employment *per se*.

Another complicated variable is *ethnicity*. At first examination, ethnicity appears to be an important influence on labor force participation. The ethnic Chinese, Hmong and Khmer refugees tend to have relatively lower labor force participation rates, while the Vietnamese and Lao have similar, relatively higher rates. These groups differ, however, in their background characteristics. After controlling for these other characteristics, the picture changes somewhat. Generally, the higher educational achievement of the Vietnamese explains their greater participation in the labor force. After controlling for education, Lao and Hmong are more likely to be in the labor force than the Vietnamese, and the Khmer and ethnic Chinese show no variation from the Vietnamese. Similarly, controlling for year of entry also increases the relative participation of these other groups. Thus, as Bach states, "the observed differences among ethnic groups in the labor market are due in large part to their diverse experiences in the countries of origin." What is significant is that these differences in background characteristics continue to cause differences in ethnic patterns even after the refugees have spent several years in the United States.

Household Size and Composition: The larger the household, the less likely are the adults within it to be seeking or finding work, again regardless of other characteristics. Refugees living alone and those living in households with multiple families tended to have higher employment rates than those living in nuclear families and extended families. ISR found, however, that the vast majority of the sample lived in nuclear and extended families.

This relationship between household size and employment can be explained in two ways. First, it is more difficult for families with large households, especially when most of the household members are children, to support themselves on the type of employment that is generally available to refugees—minimum wage jobs. Second, in large households with young children, it is more difficult for all adults to seek employment since at least one will usually have child-rearing responsibilities. As discussed below, child care programs are not generally funded through the refugee program.

Public Assistance Policies: Public assistance policies and practices exert a significant influence on refugee employment. Of interest here are both benefit levels (that is, the size of the welfare grant available to refugees) and eligibility criteria (particularly, whether refugees qualify for Aid to Families with Dependent Children (AFDC) on the same basis as other U.S. residents).

Residence in a state with a generous public assistance system depresses employment rates. Refugees living in California and other high benefit states—particularly those that permit two parent families to receive AFDC—are generally found to have lower participation rates than those residing elsewhere in the United States. Conversely, refugees living in Texas and other states with low benefit levels and restrictive eligibility guidelines tend to have higher labor force participation than those living in states with the opposite characteristics.

The relationships between state welfare policies and employment is not a new phenomenon. The depressed employment rates found in states with generous welfare benefits, particularly California, have been documented in studies of the experiences of Southeast Asians who have arrived since 1975. As one study looking at the 1975 arrivals noted: "Residence in California, happy or not, does not correlate with economic success; the California welfare system appeared to sap refugees' economic energies" (Baker and North: 1984).

An issue that is still not fully resolved by the research, but much debated politically, concerns the effects of linking cash and medical assistance for refugees (Forbes: 1984). Generally, refugees do not cite health problems as a reason for not participating in the labor market. Nor do refugee health care patterns show heavy reliance on medical services. A recent study of health service utilization patterns concluded that refugees, after their first three months in the country, tend to use health services at a lower rate than other U.S. residents (August: 1984). This finding is in accordance with research on other immigrant and minority groups.

Although actual utilization is low, refugees appear to take the prospect of losing medical benefits into account in determining whether to take jobs that do not provide medical coverage. The evidence here is mostly impressionistic. Service providers often cite loss of Medicaid or Refugee Medical Assistance as an important disincentive to early employment, as do refugee leaders. Their concern is upheld by an examination of the replacement cost of Medicaid coverage. The monetary value of the Medicaid benefit that accrues from eligibility for cash assistance is substantial: $702 per year by one calculation and $629 by another. In many states, if Medicaid benefits are lost, the net gain in income from working at a job that pays as much as $5 per hour is reduced to zero. (Henderson and Lerman: 1983)

Sponsorship: All refugees who come to the United States are sponsored by voluntary agencies that have been resettling refugees since the end of World War II. Most agencies work through a variety of different sponsorship models, using relatives, American families, congregations and professional staff to assist the refugees.

The bases for using voluntary agencies in resettlement were described by North, Lewin and Wagner in "Kaleidoscope," a study of the voluntary resettlement agencies: (1982)

(1) The volags are *there* and likely to stay, providing capacities and continuity lacking in public agencies.
(2) They are more flexible in size and in function than units of government.
(3) They bring private resources to bear, as governmental agencies cannot.
(4) They attract, and keep, dedicated staff people.
(5) They avoid a potential bias towards welfare, which might be found in the human resources agencies.
(6) They are knowledgeable about, and sensitive to, ethnic differences and the special problems of refugees.

The authors concluded that these assumptions largely remain valid, though it was difficult to document some of the claims, particularly regarding private resources. A recent study by Church World Service, "Making It on Their Own," attempted to document contributions by CWS sponsors and congregations, showing an estimated $133 million in cash, goods and services (1983).

The research on the relationship between specific terms of sponsorship and employment outcomes is inconclusive. ISR found no independent influence on self-sufficiency by sponsorship model. On the other hand, Bach found a significant effect. His study indicated that, after controlling for other variables, refugees resettled by an American family have higher labor force participation rates than do those assisted by relatives, congregations or professional staff. The differences in findings may be explained by the measures used in the two studies. ISR examined public assistance utilization and income, whereas Bach looked at labor force participation. It is possible that refugees sponsored by American families are more likely to *look* for work, but they may be no more likely to find employment that takes them out of poverty.

Training Programs: The research suggests that participation in language and other training programs is likely to influence entry into the labor market, with those in training less likely also to be in the labor force. The causal relationship between service use and labor force participation is a difficult one to measure, however. It is unclear if refugees are in training programs because they do not feel that they are ready to seek work, or if they do not seek work because they are in training programs. Whatever the direction, the value placed on education and training is clear from the research findings. In the 1984 survey of Southeast Asian refugees, almost 30 percent of the 25 to 34 year old refugees and 86 percent of the 16 to 24 year olds cited the pursuit of education as the major reason for not seeking work. Interestingly, only 10 percent cited limited English as the reason for not seeking jobs. The refugees' desire for education, or for the general skills that accrue from training programs, may be stronger than their perception of a problem (such as lack of English), that education will help solve.

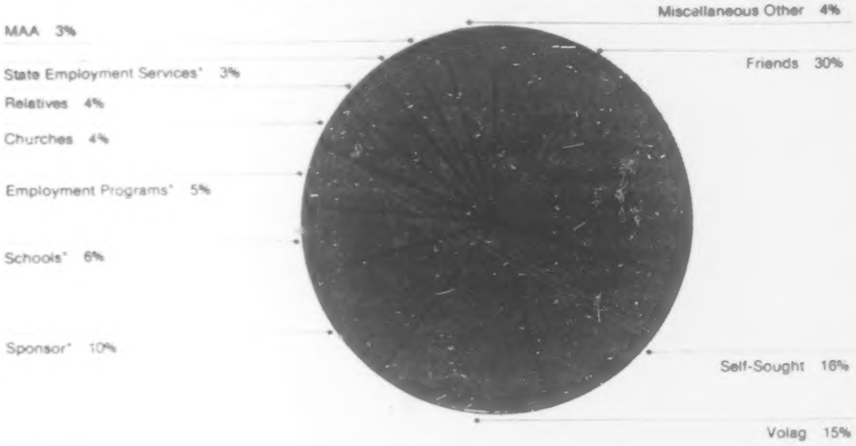
Another indication that training is likely to retard entry into the labor force comes from an examination of improvements in English language proficiency. When looking at refugees who arrived in the same year and controlling for other characteristics, it appears that improvements in English are negatively associated with labor force participation. In other words, the greater the improvement in English between the time of entry and the time of the survey, the more likely it is that the refugee is not seeking work. Studies have shown that enrollment in language training, as compared with employment, is most likely to lead to improvements in language proficiency.

It is likely, at least in the short-term, that the negative relationship found here between improvements in English and labor force participation occurs because enrollment in these training programs is a substitute for job searches. These findings indicate that training and employment are sequential activities rather than simultaneous ones. Refugees first attend language training programs and, then, when they have completed their training, they look for work.

Employment Services: Refugees find employment through a variety of sources, among them family and friends, sponsors, employment services, and their own initiative. Most studies indicate that the informal networks of ethnic and American associates more frequently result in job placements than do the more formal job services. ISR, in a finding that parallels other research, found that half of the sample of recent Southeast Asian arrivals had found their employment through personal contacts (friends, relatives or own activities) and another 14 percent through American sponsors and local churches; only 29 percent attributed job placements to formal employment services and resettlement agencies. (See Table VII.)

ISR examined use of employment services by refugees in greater detail. The services covered included everything from orientation to the American job market and workplace to assistance in identifying jobs to actual job placements. Thirty percent of the refugees received employment services, with 31 percent of these receiving them from resettlement agencies, 31 percent from government agencies, 18

TABLE VII How did you get that job?



*Non-volag

Source: Institute for Social Research, "Southeast Asian Refugee Self-Sufficiency Study, Final Report," 1985.

percent from schools and 20 percent from other providers. Nearly half the refugees in Chicago and Seattle received these services, compared to only 9 percent in Houston. Men reported a higher use than women did. Students, farmers and housewives were less likely to receive employment services than were those in other occupations. Users of employment services were also more likely to have better English proficiency at the time of the survey and to have been in the United States slightly longer than non-users.

In general, it appears that employment services are more often used by those who come to this country with greater skills and who have better access to U.S. job markets.

Economic Conditions: Employment rates, more than labor force participation rates, reflect general economic conditions as well as refugee characteristics and experiences. An examination of the employment history of refugees who arrived in 1975 shows that these relative newcomers have been adversely affected by recent economic difficulties in this country. As Table IV indicated, in 1981, the unemployment rate for 1975 arrivals stood at 6.4 percent, lower than the U.S. rate of 7.5 percent. By 1982, however, the effects of the recession had been felt, and this group's unemployment rate increased to 12.7 percent, higher than the U.S. rate of 9.9 percent. In 1983, the 1975 arrivals' unemployment remained high (12.1 percent). It is only in 1984, when the economy showed significant improvement, that the unemployment rate fell to 6.3 percent, again lower than the overall U.S. rate.

Yet, even during an economically troubled period, time exerts a strong beneficial influence on employment. More recent arrivals, although also affected by the recession, were able to make significant progress in increasing their employment, at the same time the employment rates of those who entered before 1979 were going down. Between 1981 and 1983, the unemployment rates of the 1981 arrivals declined from 45.2 percent to 40.7 percent to 16.8 percent. Between 1982 and 1983, the unemployment rates of the 1982 arrivals declined from 62.5 percent to 30.4 percent.

It would appear that during their first few years in this country, refugees' employment patterns are primarily controlled by factors related to their refugee status and experiences, and to policies regarding their eligibility for public assistance. With each year in the country, they are more likely to be employed, until they reach what could be termed equilibrium with general U.S. rates. After this point, the likelihood of continued employment is more affected by conditions in the U.S. economy than by their refugee status. As newcomers, refugees may find themselves subject to "last hired/first fired" rules, but this phenomenon equally affects other populations.

Public Assistance Utilization

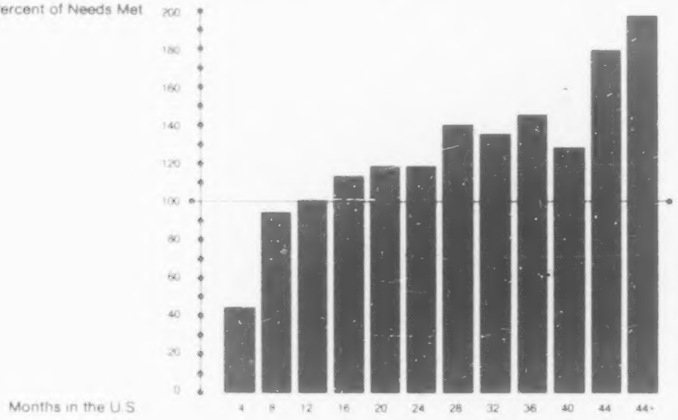
As of the end of FY 1984, about 54 percent of refugees who had been in the United States for three years or less were receiving some form of cash assistance. Welfare utilization rates vary greatly from state to state. For example, in California, over 85 percent of the refugees in the United States for three years or less are estimated to be cash assistance recipients. In Texas, on the other hand, less than 20 percent of these refugees are receiving public assistance.

Welfare utilization patterns also differ by nationality. Southeast Asian refugees, by and large, have higher utilization rates than do refugees from other regions. According to the Office of Refugee Resettlement, the best estimates are that 60 percent of Vietnamese and Lao and 49 percent of Khmer refugees, in this country for less than three years, receive cash assistance. The rates for refugees from Eastern Europe (excluding Poland), Afghanistan and Iraq are in the low 30 percent range and those for Soviets and Ethiopians in the high 20 percent range. Refugees from Poland have welfare utilization rates of about 20 percent.

Most information available on patterns of welfare use over time pertain to Southeast Asians. The capacity to become independent of public assistance programs, as with employment, improves over time. According to the ISR study, whereas almost 80 percent of those in the United States for less than eight months were found to be fully dependent on public assistance, only about 30 percent were fully dependent after three years. The percentage of those living on earned income only rose from three percent in the first four months to about 50 percent after three years. The annual survey of Southeast Asians shows similar findings. About 70 percent of those in this country for less than six months live in households receiving cash assistance; for those in the United States for over 36 months, this group has dropped to 39 percent.

For a household to become independent of public assistance generally requires multiple wage earners. As ISR notes, "dramatic changes in economic status occur when additional people take jobs rather than from changes in wages through the job advancement of a single individual in the household." Of households with no employed member, 17 percent were above poverty level; 68 percent of the households with one job and 93 percent with at least two jobs were above poverty level.

TABLE VIII Percent of Poverty Standard Met By Total Household Income



Source: Institute for Social Research, "Southeast Asian Refugee Self-Sufficiency Study. Final Report," 1985.

Income

Refugees are now having problems finding jobs that pay enough to take them out of poverty. In a study "Refugee Earnings and Utilization of Financial Assistance Programs" David North concluded that "the wages and earnings of the refugees clearly place many of them in the lower tiers of the U.S. labor market (North: 1984)." Moreover, in examining survey data from 1981, 1982 and 1983, he found that average weekly wages *decreased* during the recession.

ISR found that 50 percent of the households they sampled fell below the federal poverty level. Over time, however, refugees are likely to rise above this line. In Table VIII, for example, households in the United States for four months or less had income that was only 46 percent of the poverty level, whereas those in the country for 36 months had income that was one and one half times the poverty line.

Whether a refugee household is above the poverty level is affected by the source of the household income. The majority of households that were solely dependent on public assistance programs were below the poverty line. Households with combined earnings and assistance income tended to be just above the poverty line, and those with earned income only were the most likely to be well above the poverty level, although even 12 percent of these refugee households remained below the poverty line.

The likelihood that refugee households have incomes that place them above the poverty line is determined by a number of factors. Not surprisingly, small households fare better financially than large ones since it is more likely that minimum wage employment will bring a small household out of poverty. So too do households with more than one employable adult since multiple wage earners are needed to raise earnings above the poverty line.

Also strongly affecting the economic status of the household is English proficiency on arrival. After controlling for other factors—e.g., previous education and occupation—refugees who had a higher level of English on arrival were more likely to live in a household whose income was above the poverty level.

This finding, in combination with Bach's conclusion that English proficiency has little independent effect on labor force participation, shows the complexity of the relationship between language and economic adaptation. It may be that knowledge of English does not have a significant, independent effect on the capacity of a refugee to seek and even find jobs, but that it does affect the capacity to earn sufficient wages to raise the household income above poverty level.

English Language Proficiency

Knowledge of the English language is important, as we have just examined, in economic adaptation, and it is a prerequisite for full participation in U.S. institutions. Federal refugee policy promotes implementation of programs aimed at increasing English language acquisition. The Refugee Act recognizes that language training serves an important function apart from its relationship to employment. In the Act, the Director of the Office of Refugee Resettlement is authorized "to provide training in English where necessary (regardless of whether the refugees are employed or receiving cash or other assistance)." A substantial portion of funds used for social services is earmarked for language training in the United States. In addition, language training is provided in overseas camps to refugees who are bound for this country. Given the emphasis on language training, an examination is warranted of the extent to which English is acquired by refugees.

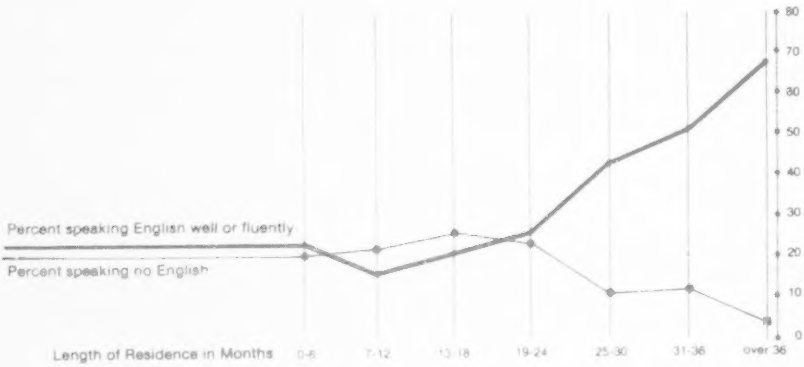
Arrival and Current English

Most Southeast Asian refugees, at the time of entry, have very limited English language proficiency, with anywhere from one-third to two-thirds of all new arrivals speaking no English at all, depending on the survey and the year of arrival. According to the annual telephone survey of Southeast Asian refugees, the range in percent of refugees speaking no English has been between 40 and 50 percent since 1975. On the other hand, ISR found that 64 percent of new arrivals spoke no English at the time of entry.

In 1975 a significant proportion of refugees (about 30 percent) spoke English well or fluently upon arrival, but the proportion of such refugees has been far lower among the post-1979 arrivals (about 7 percent). In recent years, with the advent of overseas language training, the percent of refugees who speak English well has risen modestly to 9.2 percent.

English proficiency on arrival is strongly influenced by background characteristics, including previous education, previous occupation (professionals, military personnel, clericals and students having a higher level of English), gender (men arrive with significantly better English skills) and age (older refugees having less English on arrival). It is also influenced by training in overseas camps, with those receiving such training arriving with higher English skills than those who do not receive it.

TABLE IX Patterns in the Adjustment of Southeast Asian Refugees



Source: ORR Annual Report to Congress, January 31, 1985.

Over time, the proportion of refugees who become fluent in English increases. Among those in the United States for 31 to 36 months, according to the Southeast Asian telephone survey conducted in October 1984, 51.4 percent speak English well. (See Table IX.) These refugees arrived in the United States in 1981 and 1982, when the level of pre-arrival English was very low. ISR also found gains in English proficiency, with 88 percent of the sample showing some English ability at the time of the survey, as contrasted with 37 percent on arrival. Only 4 percent had spoken English "very well" or "fairly well" on arrival; at the time of the survey 20 percent believed they spoke English proficiently.

Although the proportion of refugees who speak no English shows signs of improving over time, a core appear to make little, if any, gains. According to the telephone survey, approximately 20 percent of those in the country for almost three years still speak no English by their own evaluation.

Factors Influencing Gains in English

Acquisition of English in the United States is influenced by a combination of personal characteristics and training. A survey conducted by the Northwest Regional Educational Laboratory (NWREL), "A Study of the Extent and Effect of English Language Training for Refugees," examined these factors through a community survey of refugee households and a longitudinal study of a selected group of refugees who had recently arrived (NWREL, 1982-1984).

Background Characteristics: Previous *education* continues to exert a strong influence on language proficiency, as does *gender*. *Literacy* in another language also positively affects gains in English. The strength of these relationships is apparent in looking at the proportion of refugees who believe they have sufficient English to look for a job. Only 6.3 percent of those with no previous education considered themselves to have this English competency whereas 77.3 percent of those with 12 or more years of education so defined themselves. Similarly 15.8 percent of those who were illiterate in their native language, in contrast to 53.7 percent of those who were literate, believed they had enough English to look for a job.

Training versus Employment: Within the refugee field, there has been a persistent debate about the relative impacts of language training and employment on gains in English proficiency. Some have argued that refugees will learn English more quickly if they are enrolled in full-time classes, whereas others have argued that employment, or a combination of employment and training, will stimulate greater acquisition of English skills.

NWREL found that among people of similar backgrounds, those who take language training acquire more English than those that do not. Language training was found to be a more significant predictor of English gains than is employment. The longitudinal survey followed four groups of refugees: 1) those who were in language training only; 2) those having a combination of training and work; 3) those in work only; and 4) those participating in neither. Those in some type of work experience generally started at a higher level of English than the others. At the end of six months, the gains in English displayed by those in full-time language training were significantly greater than those in employment, with the training group surpassing the language ability of the employed group by the end of the period.*

Availability of Language Training in the U.S.: For the most part, language training is now widely accessible in the United States. NWREL found that 74 percent of the adult refugees in their sample had received language training in the United States, with the average number of hours of instruction being 681 for those participating in classes. ISR had similar findings: 75 percent of the adult refugees sampled had or were receiving language training. Those that had completed their training reported an average of 600 hours of attendance. Almost two-thirds had taken an elementary class, 25 percent an intermediate one and 10 percent an advanced one.

Utilization of language training differs by gender and age. In all age groups, men are more likely to attend class than women (81 percent vs. 67 percent in the NWREL sample). Younger refugees are also more likely to receive training, with refugees who are over the age of 50 being the least likely to be enrolled.

Refugees with no previous education are less likely to be receiving language training and they have fewer hours of instruction in this country. ISR found that those with college degrees are also less likely to be in language training programs, presumably since they are more likely to know English. In both samples, those most likely to be receiving extensive language training are refugees with some education, the NWREL study showing that these refugees received an average of 752 hours of instruction.

Utilization further varied by location in the United States. Refugees in California (Orange County in one sample, Stockton in the other) were more likely to be enrolled in programs than those in Houston or Denver. The latter two sites had significantly more employed refugees than the California sites. As was shown above, language training and employment tend to be sequential activities. Thus, where relatively large numbers of refugees become employed early in their resettlement experience, relatively fewer are enrolled in language training; conversely, where larger numbers are receiving public assistance, more are receiving training.

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*The NWREL study followed a group of refugees enrolled in what were considered to be model language training programs where the level of instruction was notably high. Were a similar study to be done at randomly selected programs, the findings may not correspond.

NWREL found that the percentage of refugees who are employed and participating in language training (15 percent) is half the percentage of those who are not working (31 percent). This can be explained in two ways: the needs of the refugees and the policies governing eligibility. First, refugees who already speak English—and therefore have less need of language training—are more likely to be employed; further, refugees who are employed have less time available for training activities, particularly since most classes run for about three hours per day, four days per week. Therefore, employed refugees are less likely to either need or have the time to use language training programs. Second, most language training programs give priority to new arrivals, recipients of public assistance and people who are not yet employed. Refugees who are already employed, even if marginally, are not high priorities for language training programs.

Ethnic Community Development

Ethnic community development is a complicated measure of adjustment. Ethnic support structures serve as intermediaries between the new arrival and the general U.S. society, helping the immigrant learn of mainstream expectations and communicating ethnic interests to decision-makers and institutions outside the community. Since the founding of this nation, ethnic communities thus have played an important political and economic role in supporting the aspirations of their members.

Ethnic community development may be at odds, however, with expectations about the integration of refugees into the broader U.S. society. The concept of the "melting pot" still holds much force in this country. The capacity to socialize with native-born U.S. residents, and the interest in doing so, are important marks of cultural and social assimilation. (Economic adaptation may operate apart from social assimilation, with members of a separate, ethnic enclave able to support themselves without reliance on public assistance.)

A recent study by SRI International (SRI) examined the role of the Southeast Asian ethnic community at the local level. (SRI: 1983) The study found that these communities share some common elements, regardless of ethnicity. Informal social networks, particularly familial ones, are at the heart of the ethnic community. But refugees set up more formal organizations, too, including religious institutions, businesses and self-help organizations. These latter institutions, generally termed mutual assistance associations (MAAs), serve several purposes. Some are primarily social or cultural in nature, while others offer educational, employment and other services to their members and the broader ethnic community. Some are supported by the community itself, while others receive funds from non-refugee sources, including government agencies.

The number of self-help organizations varies by nationality, the characteristics of the refugee population, and location—though not necessarily by the size of the refugee community. SRI found, for example, that metropolitan Washington, D.C. and Orange County, California have far more MAAs, relative to the size of the community, than does New Orleans. Washington and Orange County have long-standing Vietnamese communities that are economically successful, with a high proportion of residents who were leaders in Vietnam. On the other hand, a greater proportion of rural, more poorly educated Southeast Asians settled in New Orleans.

Most of the MAAs examined by SRI were not particularly active. Few brought members together regularly or had a consistent set of activities. Similarly, few refugees report active involvement in MAA activities, although a higher number are officially members of these organizations and a still higher number use their services.

Over time, the development of MAAs into service organizations has increased. The federal government has provided incentive grants to states to encourage them to fund refugee organizations as service providers. A recent initiative, its impact has not yet been evaluated.

SRI found that ethnic communities play a role in assisting refugees toward both social and economic adjustment. ISR's study of self-sufficiency also emphasizes the ethnic community, and more specifically, the ethnic household as a major deteriminant of economic adaptation. According to SRI, the ethnic community serves many purposes. It is a source of social, emotional, and spiritual support at a point at which many refugees are confused about their futures. It is also a source of more tangible support. Refugees within a given ethnic community pool money for both living expenses and to begin business ventures. The community thus serves as a surrogate banking institution. Moreover, shared housing is used to minimize expenses and increase the likelihood that employment will lead to self-sufficiency.

SRI examined the interactions between refugee and nonrefugee communities. Language and cultural barriers, not surprisingly, were found to hamper these interactions. And refugees have often been perceived to be isolationist, wanting to socialize primarily with members of their own nationality. There is evidence, however, that social assimilation is taking place over time, especially among the younger generation.

The refugee community, through both its informal and formal networks, provides direct services to members of the community. As noted above, MAAs are now important sources of educational services, employment services, translation and interpretation, mental health services and others. Moreover, the ethnic community structures help refugees access other services. Perhaps, most important, it is through informal refugee networks that many refugees find jobs, having been referred to employers by other refugees.

The effectiveness of ethnic organizations is influenced by a variety of factors: for example, their financial resources; the capacity of their leaders and staff to perform the functions expected of them; divisions within the community that can fragment service delivery; the ethnic community's knowledge of services and programs outside of their own network; and the needs of refugees for the services provided by MAAs.

SRI concluded that the forms of support offered by the ethnic community are crucial in the adjustment of refugees. As SRI stated:

> On the whole, the intangible and tangible support provided by the community

> positively affects the social and economic adjustment of refugees, even though some refugees might become socially isolated by relying exclusively on the community for support.

In this respect, the Southeast Asian community is following a pattern previously adopted by many other immigrant groups.

PATTERNS OF RESIDENCY AND THE IMPACT OF REFUGEES

Policy makers and program implementors have long been concerned with issues pertaining to the geographic distribution of refugees and their impact on U.S. communities. Questions about these patterns have been asked at every recent Congressional hearing on refugee legislation and admission levels. Understanding these phenomena is key to policy planning regarding three major issues:

- Admissions decisions—The Refugee Act of 1980 requires that information be provided, during the consultations on refugee admissions numbers, on the anticipated social, economic and demographic impact of refugee admission to the United States;
- Placement policy—U.S. placement policy states that "the distribution and placement of refugees shall be done in a manner which will reduce further the impact on certain communities and avoid creating new areas of high impact in the future"; and
- Federal reimbursement of state and local costs—An explicit aim of the refugee-resettlement program is to ensure that no state or locality bears an undue financial burden because of the admission of refugees to the United States.

Patterns of Residency

Where refugees live in the United States is determined by two major factors, each of which is influenced by several other factors. First, refugees are *placed* in U.S. communities upon their entry into this country. After initial placement, some refugees relocate, moving to new communities within the state of original settlement or to different parts of the country. This is referred to as *secondary migration*, the second factor affecting geographic distribution.

Since 1945, official and informal U.S. refugee placement policy has aimed at dispersing refugees throughout the country, in order to minimize negative impacts on receiving communities and hasten self-sufficiency. While the initial placement of refugees may be controlled by federal policy, secondary migration is more difficult to control through either policy or programmatic interventions. These later movements of refugees may occur, however, as an unintended consequence of policy changes.

Residency Patterns of 1975 Arrivals

In 1975, when the first Southeast Asians were resettled, special efforts were made to settle them throughout the nation. Because of this conscious decision, their pattern of settlement was much closer to that of the general U.S. population than to previous refugee groups or other immigrants. About 57 percent were placed in 11 states, which each received more than 3,500 persons. California was the principal state of resettlement, receiving over 20 percent of the newcomers.

In 1975, placement decisions were made on the basis of a number of factors, including the preferences of the refugees (generally for urban areas, places with an existing Asian population and a warm climate) and the availability of sponsorships (generally in metropolitan areas, near military or government installations and favorable employment prospects). About half of the refugees were placed where they requested, whereas the rest were sent to other locations.

Fully 45 percent of the 1975 arrivals relocated by 1980. Generally, secondary migration was in the direction of the West and South, in conformance with general U.S. patterns of the same period. Secondary migration tended to lead to greater concentrations of refugees, as persons in small refugee communities moved to those with larger refugee populations. While initially only 8.5 percent of the refugees lived in areas with more than 3,000 refugees, by 1980, 20 percent lived in these areas.

Those refugees who were settled where they requested were less likely to move than the other refugees. A negative resettlement experience, including long stays in reception camps and difficulty in finding a sponsor, was positively associated with secondary migration. States with restrictive cash assistance policies tended to lose refugees, and states with good employment prospects, a large Asian population and high welfare benefit levels tended to gain refugees. Although background characteristics had a marked effect on economic adjustment and language acquisition, they had relatively little effect on secondary migration.

Residency Patterns Since 1979

The placement patterns of refugees who have been resettled since 1979 show a higher level of concentration than was true of those who arrived in 1975, but because of the great dispersal that took place that year, the Indochinese refugees are still more dispersed than other immigrant populations. The current geographic distribution of refugees upon arrival has been influenced by the following factors:

- Placement policy that recognized the legitimacy of family reunification, leading to placement of most Indochinese refugees in areas that already had high concentrations of refugees;
- Formal placement policies that reduced the placement of refugees without family ties into high impact areas and encouraged the development of new resettlement sites, through the Khmer Guided Placement Project and the Favorable Alternative Sites Project (Berkeley Planning Associates: 1984); and
- A growing diversity in refugee populations that are now being settled. This has contributed on the one hand to high concentration (since most non-Indochinese refugees are more highly concentrated than the Indochinese) and on the other to the introduction of new refugee resettlement sites (i.e., places which received few Indochinese refugees but are receiving large numbers of other groups).

Less information is available on the secondary migration patterns of more recent arrivals than on the 1975 Indochinese refugees. Since 1982, aliens are no longer required to register each year with the Immigration and Naturalization Service; therefore a valuable data source on secondary migration has been lost.

Current analyses of secondary migration are based on reports from public assistance agencies.* These show:

- A total of 94,622 refugees, or 73 percent, receiving assistance were living in the state in which they were resettled initially.
- Of the 34,422 refugees (27 percent) who had moved to another state, nearly 22,000 (63 percent) had moved to California. New York was the second favored destination, attracting 2,444 people, or 7.1 percent.
- Almost all states experienced both gains and losses due to secondary migration. Even states with as few as 23 refugees (Delaware, for example) attracted individuals from other states.
- Outmigrants counted in this survey represented 15.2 percent of all of the refugees who arrived from July 1981 to June 1984. In about 15 states, a much higher than average proportion of arrivals left the state and sought assistance in another state. Most of these states have more restrictive welfare eligibility criteria and/or lower benefits and/or no general assistance program. In several other states, a much lower than average proportion of arrivals left the state and sought assistance elsewhere. These states generally have liberal cash assistance policies and high benefit levels and/or they are states that have resettled large numbers of non-Indochinese refugees.
- There was a substantial amount of population exchange between contiguous or geographically close states. This pattern is consistent with general migration patterns.

Finding extensive population movement into California was not unexpected. Several factors, in addition to those which we have already seen in the examination of the secondary migration of the 1975 Indochinese arrivals (i.e., presence of family members, draw of the ethnic community, climate, etc.) have contributed to that pattern:

- Cash and medical assistance policy changes that led to the termination from assistance of large numbers of refugees in Washington and Oregon, a significant portion of whom moved to California; and
- The decision on the part of the Hmong community to establish a new community in the Central Valley of California.

Impacts of Refugee Resettlement

The concentration of refugees in a few locations has raised the question of the impact of resettlement on these places. As a recent study by SRI International pointed out, "impact has become an emotionally loaded term for the negative effects that refugees have had on localities." Of course, impacts can be positive or negative. And they can involve any number of effects that can stem from resettlement. SRI identifies seven sectors of local communities that are likely to be affected: housing and neighborhood environment; employment; public assistance; educational services (K-12); adult educational and employment services; medical services and mental health services. The study also describes four ways in which the impacts can occur:

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*States have been asked to report on the Social Security numbers of their assistance caseloads. The first three digits gives information about where the card was issued. Since most refugees receive a Social Security number soon after entry, these numbers are a good indicator of where a refugee was placed in comparison to where he or she is receiving assistance. Although the data have certain drawbacks—particularly that they pertain only to refugees receiving assistance—they do permit an examination of secondary migration trends among a special subclass of refugees.

> "First, population shifts can occur, as people move to accommodate newcomers. Second, changes in the structure and staffing of social, educational, and medical services can occur as agencies respond to the special needs of refugees. Third, changes in financial resource allocation in localities can result from the introduction of refugees or the refugee program. Fourth, changes can occur in interactions between residents that affect community relations in localities." (p. 114)

Not only are impacts multi-dimensional, but they change over time. What may be short-term costs can turn into long-term benefits to a receiving community. In fact, at any given time, the impact of refugees may be mixed, with certain sectors of a community absorbing costs and others benefiting from the presence of the new population.

Housing

The most immediate effects refugees have had on some locations were with respect to housing. As refugees moved into various neighborhoods, there were shifts in the character and composition of the residential areas. In many places, refugees did not displace other residents, however, since they moved into transient neighborhoods or areas with high vacancy rates. Where there has been competition for scarce housing, community tensions have risen, particularly vis a vis other minority groups.

State and Local Costs

Local services have also been affected by the presence of large numbers of new refugees. Service utilization translates into state and local costs. These take two forms: 1) costs directly attributed to a refugee population, such as unreimbursed costs of health services provided to refugees; and 2) costs of the increased demand for services that an increase in population entails. A study in Orange County, California refers to these latter costs as "secondary fiscal impacts" (Orange County: 1981).

The SRI study looked at costs incurred by states and localities pertaining to public assistance, education, employment services and health and mental health services. The study concluded that local costs are hard to document, partly (as discussed below) because many costs are covered by federal funds and partly because costs attributable to refugees may be hidden within budgets that cover services for other populations. As far as could be determined, local costs appeared to be low, but there was concern that they will rise substantially when federal support ends.

The costs of some services are difficult to calculate because additional population can be either an advantage or a disadvantage. Some states and localities have cited the costs of education as a major expense associated with resettlement. The State of Florida, for example, calculated that the costs for public education for Mariel Cubans was $126 million in 1980 and 1981. Other jurisdictions have shown little concern about the cost of providing schooling to refugees.

The difference in approach is often related to school capacity. In a district in which schools are filled to capacity, additional population means either the classes will be over-crowded or extra funds will be needed for additional facilities and staff. On the other hand, in a district with underutilized schools, additional population may mean more effective use of existing resources. The SRI study notes that some districts with declining enrollments welcome refugee children because the added population increases their state funding and may prevent the closure of some schools.

Of most concern to state and local officials are the unreimbursed costs of cash and medical assistance provided to eligible refugees. The costs of AFDC and Medicaid are only beginning to be felt now, since the majority of refugees have been covered under federally-funded programs. During the time of the greatest migration of refugees (1980-1981), costs to the states and localities of public assistance were low. Orange County estimated, for FY 1981-82, that the county's costs for public assistance would be $556,924 and the state's cost for the refugees in that county would be $2.6 million; the federal share would be $54.6 million. County and state shares have increased since that time, particularly in areas such as California, where refugees have not become economically self-sufficient in three years.

A related area of concern has been the cost of providing public health services. In this case, though, local impacts have decreased over time. A 1982 study by the General Accounting Office (GAO) reported that local health departments were absorbing significant additional costs in providing refugees with services not covered by the federal refugee program. It cited Fairfax County, Virginia as one location with mounting costs that could be attributed to meeting refugee public health needs. According to GAO, from August 1979 to April 1981, Fairfax spent about $270,000 to provide refugees initial health screening; blood, parasite and tuberculosis tests; and immunizations. Only about $61,000 was reimbursed through the refugee health program. Los Angeles and Orange Counties, California, and the District of Columbia, among other locations with large numbers of refugees, had had similar problems.

Three factors have contributed to decreasing the negative impact on local public health facilities. First, the number of new arrivals—that is, the population most needing screening and treatment—has decreased significantly in the past two years. Second, the federal government provided special grants for health screenings and assessments. And, third, improvements were made in the overseas screening program to identify and treat problems before refugees arrived in local communities.

Federal Revenues

State and local costs have been greatly reduced by federal reimbursements, which may even contribute to a net gain in revenues. Yet studies of impacts have tended not to look too closely at the flow of federal funds, except insofar as federal funds reimburse or fail to reimburse specific costs of resettlement. The effect of the federal dollars themselves tends not to be examined, even though the refugee program is one of only a few programs in operation that relies fully on federal funds.

Federal funding of refugee programs takes several forms and comes from several government agencies. Some federal funds come through refugee-specific programs authorized by the Refugee Act of 1980, while others come from mainstream programs in which the level of funding is tied to the number of people utilizing the service. Still others have been funded through the Fascell-Stone Amendment to the Refugee Education Assistance Act of 1980 which provided authority for reimbursing costs incurred on behalf of Cuban-Haitian Special Entrants.

The federal expenditures take several different forms. Some are grants-in-aid to the refugees, which are passed through public and private agencies; a portion of the R&P grants, matching grants, food stamps and cash assistance are in this category. Most of these funds are spent in the state in which they are issued. In other words, a refugee receives a monthly cash grant and uses it to pay for rent, food, clothing, utilities, and other necessities. Other federal funds are used to support direct services, while still others support the administrative structures needed to implement refugee programs.

Federal funds assist not only the refugee but also the merchant from whom the refugee buys goods. Service delivery agencies and government offices involved in resettlement activities also benefit; these federal funds provide for the employment of professional and clerical staff. Federal revenues indirectly aid the state and localities, since a portion goes to taxes (real estate taxes paid through rent payments, sales taxes paid through purchase of goods, and income taxes paid by those employed in refugee services). Thus, federal revenues have a broad positive impact on the states and localities receiving refugees.

Tax Payments by Refugees

Refugees contribute to public revenues in direct ways as well. Refugees pay a wide variety of taxes, including (depending on the place of residence) income taxes, property taxes, sales taxes, motor vehicle license taxes, cigarette and beverage taxes, pari-mutuel taxes, occupational licenses and permits, utility service taxes (water, electricity, etc.), and corporate income taxes for refugee-owned businesses.

There have been no empirical studies of recent refugee contributions to state and local revenues through tax payments. A study conducted in 1976 of Cubans in Miami (Arthur Young 1976) provides some illustrative information, however, as do studies of immigrants earnings by Julian Simon (1980) and Barry Chiswick. The Cuban study identified selected taxes paid by Florida residents of Cuban origin and compared them, on a per-capita basis, with taxes paid by the non-Cuban population. It also compared the cost of providing public services (including cash and medical assistance and education) to Cubans and other Floridians. A financial impact was defined as unfavorable when Cuban residents contributed relatively less in taxes or other revenues than non-Cubans, or when a higher portion of public program costs were attributable to the Cuban than non-Cuban population. The study concluded that at the time of the study, the Cuban population would have represented a net financial negative impact if it had not been for the availability of federal funds which were directly attributable to the presence of the Cuban population. Cuban contributions to public programs through their taxes, given their use of these programs, was proportionately lower than the rest of the population. The study identified several reasons for this disparity, some related to the special needs of the Cubans (for example, bilingual education), others to the demographic characteristics of the population (for example, the higher percentage of school-age children in older families) and still others to the places where Cubans lived (for example, Dade County medical costs are higher than those in other parts of Florida). The study further found that Cuban per-capita income (the basis upon which taxes are calculated) was lower than that of non-Cubans, thereby leading to lower than average tax payments.

Because some of the factors identified in this study were already showing signs of change—most important, that the gap in per-capita income was decreasing—the authors concluded that the unfavorable financial impact would be sharply reduced over the next three to five years. Simon's and Chiswick's studies of the overall immigrant population bear this out. Using separate data sources, they found that the income of immigrants matched and then surpassed that of U.S. natives after the immigrants had been in the country for several years. Simon found that after two to six years, immigrant families pay as much, and then substantially more, in taxes than do native families. He also found that immigrants use less public service funding, largely because of differences in Social Security, than do native families from the time of their entry until about 12 years later, when their usage roughly equals that of native families. He concluded that the net balance of payment is in the public's favor; immigrants *over time* contribute more to the public coffers than they take. As described above, refugees may take longer than those who migrate for economic reasons to close the earnings gap, but previous groups of refugees have accomplished it.

Although there is no data on refugee taxes paid to states and localities, the Internal Revenue Service has provided information on the federal tax payments of Southeast Asian refugees who arrived in the United States from 1975 through the end of 1979. These data show that tax payments have increased over time. In 1980, these refugees contributed $86,644,000 in taxes; in 1981, $115,696,000 and in 1982, $114,914,000. By contrast, this group paid only $18.5 million in taxes in 1978. Since most research shows increases in earnings with greater time in the United States, the tax payments of refugees should continue to increase.

Labor Market Impacts

Few studies have focused directly on the labor market impacts of refugees. A notable exception is the study by SRI International, "Southeast Asian Refugee Resettlement at the Local Level."

There has been a significant body of literature on the labor market impacts of immigrants. Experts differ with regard to the effect on the labor market of immigration to the United States, but agree that the major group to be affected are those who are directly in competition for the same jobs. At the risk of oversimplifying so complex an issue, it is possible to group those who discuss these impacts along a spectrum of opinion. At one end of the spectrum are those who argue that immigrants take jobs in what is essentially a fixed-job universe. Their basic assumption is that immigrants take jobs that might otherwise go to U.S.

residents and/or make otherwise acceptable jobs unacceptable to U.S. workers by permitting depression of wages and working standards.

In the center of the continuum are those who argue that immigration has mixed effects that may cancel each other out. Here, the impact is seen as complex, with immigrants affecting job opportunities and earnings of different groups of natives in relation to their level of skill. As one proponent of this view, Barry Chiswick, wrote: "Immigrants do not have a uniform impact on the native population. Some native groups gain and others lose." If immigration is primarily composed of low-skilled workers, then native low-skilled workers will suffer as the result of competition for jobs while skilled and professional workers will benefit because of the additional availability of inexpensive labor and the increased demand for products and services.

At the other end are those who argue that immigration, however large, causes substantial economic growth and immigrants have a beneficial effect on the wages and employment possibilities of other U.S. residents. According to this line of reasoning, immigrants cause an expansion in the market for goods and services and thereby induce benefits to the economy. Further, migrants contribute to technological innovation and entrepreneurial activity, and, as a result, provide opportunities that might otherwise not have existed.

Extrapolating from the literature on work experience, one can come to certain conclusions about the extent to which refugee impacts are likely to correspond to those of other new arrivals. Available research shows that employed refugees are generally in unskilled jobs, regardless of their level of education, previous occupation or skills. Not surprisingly, tensions regarding labor market impacts have occurred in areas in which there is competition for the type of unskilled jobs that refugees take. Although the SRI study found that, for the most part, job displacement did not occur as a result of refugee resettlement, it did conclude that competition was increased for some jobs. Giving an example, the study noted that "tensions over jobs have tended to occur in localities with poor economies. In New Orleans, tensions erupted between Blacks and Vietnamese in 1978 when Blacks accused refugees of displacing them from jobs, housing and services. New Orleans has chronic high unemployment; Black unemployment is usually about 20 percent."

Perhaps the most prominent example of job displacement has been in the fishing industry on the Gulf of Mexico. Among the boat people leaving Vietnam were a sizeable number of fishermen who, not surprisingly, wished to continue their previous occupations. Since 1975, the number of fishing boats owned by refugees has increased in several states along the Gulf coast. Their presence has led to community tensions and even violence. Factors precipitating tensions were a combination of economic competition and social and cultural differences and misunderstandings.

As noted above, job creation can also result from the arrival of newcomers. Job creation takes place when refugees contribute to economic growth as entrepreneurs. SRI noted that refugees are just beginning to open businesses and that these are generally too small to employ many people. It cites Orange County as an exception because the Vietnamese business community is more developed there. At the time of the survey, about 2,000 jobs had been created in the 500 to 600 refugee businesses in the county.

Generally, the full impacts of recent refugees on labor markets—whether positive or negative—have not yet been felt. The majority of the Southeast Asians have been in this country for less than five years. Moreover, they tend to be younger, on average, than other U.S. residents. During much of the period they have been in this country, many of the refugees have received public assistance and have not been employed. Many have been in training programs since their arrival. As more refugees actually enter the labor force, the issue of job displacement may arise in more locations. Conversely, as more refugee businesses open, the labor market benefits of this population may be more evident where this economic development occurs.

POLICY IMPLICATIONS

Refugees from Southeast Asia are on what is likely to be a lengthy, difficult road toward full self-sufficiency. The various surveys that have been conducted make up a bleak picture of the present, with much higher than average unemployment, underemployment among those who find jobs, and substantial numbers living in poverty.

If the current picture is bad, however, there are promising signs for the future. Over time, refugees are likely to show economic progress. Improvements will come partly from what one researcher has called the "inexorable" movement to self-sufficiency. Each year a larger proportion become employed and the percentage climbing out of poverty also rises. Still more progress is likely to result from the economic recovery. Refugees were hard hit by the recent recession, with the unemployment rates of even those who arrived in 1975 climbing well above the national average. In 1984, however, many refugees appear to have regained some of the economic successes that had characterized their earlier experience in the United States.

The research shows that the majority of refugees are able to become employed, leave public assistance and increase earned income to place themselves above poverty within two years of arrival, with refugees from advantageous backgrounds and/or small households more likely to achieve these ends. There appears to be a distinct pattern of resettlement, with about three-quarters of all refugees being economically dependent during the first year, slightly more than half being in this position during the second year, and about one-third still receiving assistance by the end of the third year.

Relatively little is known, at present, about the long-term prospects or experiences of the population that does not become self-sufficient. About one-fourth of the refugees appear to remain dependent beyond 36 months. Continued reliance on public assistance has been found related to age (that is, many of those receiving income subsidies are over the age of 55) and family composition (that is, single-parent households or two-parent families with large numbers of children). Even within the overall U.S. population, these groups are the most likely to require long-term assistance. Whether these refugees will be able to become economically independent at a later point in their resettlement experience—and what effect, if any, their prolonged use of public assistance will have on the next generation—is still to be seen.

Whether the overall refugee resettlement program is seen as a success or failure is, in part, determined by what one believes about the rapidity with which refugees can become self-sufficient. While there is general agreement that self-sufficiency should be the goal of the resettlement program, there is less agreement about timeliness and mechanisms for achieving this objective. Much of the debate has focused on the relationship amongst early employment, welfare utilization and long-term economic self-sufficiency. On the one side are those who argue that refugees need a transition period in this country, during which they should receive training to help them in their long-term adjustment. Generally, public assistance is seen as a necessary mechanism to provide interim income support to refugees while they are preparing themselves for the future. On the other side of the debate are those who argue for the earliest employment possible for refugees. Underlying this position is the belief that employment within a few months of arrival is 1) the best route to long-term self-sufficiency and 2) necessary in order to decrease the overall costs of the resettlement program. Often, public assistance and training programs are seen by the proponents of this position as impediments to self-sufficiency.

For the most part, the timelines for achieving self-sufficiency have been set through policies governing federal reimbursement of the costs of public assistance. These policies stem only in part from concerns about refugee adaptation. Equally pressing is the desire to minimize potential state and local costs. At present, refugees have special eligibility for public assistance for the first 18 months after their arrival; if they are categorically eligible for Aid to Families with Dependent Children (AFDC) or General Assistance programs, the costs of providing this assistance are reimbursed for an additional 18 months.

Since expectations about self-sufficiency have been set through reimbursement policy, budgetary and political considerations have played a strong role in determining the route to and number of months within which refugees are expected to become economically independent. These factors are likely to continue to exert a major pull on policies. Their importance should not, however, mask the fact that policies that make political or fiscal sense may not necessarily be in accordance with actual or possible patterns of adjustment.

Unfortunately, in setting policies geared toward the attainment of self-sufficiency, research is of limited use. The various studies examined in this report demonstrate the complexity of the relationship between employment and self-sufficiency. It is important to note that for many refugees who can and do become employed within a few months of arrival, early employment will not always translate into self-sufficiency. Refugees who are receiving public assistance are not necessarily unemployed. They may be receiving supplemental assistance because their earnings do not give them sufficient income to make them ineligible for public aid. Nor are refugees who are not receiving public assistance necessarily economically secure. As we have seen in one survey, 12 percent of the refugees who relied solely on employment had incomes that placed them below the poverty level. Whether these refugees should be considered to be "self-sufficient" is a matter of definition.

It is not clear from these studies, moreover, whether the curve of self-sufficiency can be compressed, with refugees perhaps following the same pattern but in fewer months. Nor is it clear whether early employment versus training leads to long-term self-sufficiency. The research is constrained by the very policy choices, in terms of public assistance programs, that are under examination. The policy governing eligibility for special programs, as well as the assumptions of service providers about the feasibility of refugees achieving self-sufficiency, will themselves determine the length of time between arrival and self-sufficiency. For example, service providers often report an upsurge of job-hunting activity among refugees who have been in the United States for 16 or 17 months. Knowing they are about to lose their eligibility for public assistance, a more serious job search begins. Similarly, many refugee service programs target their efforts at those who about to lose their eligibility for public assistance and spend relatively little time with newer arrivals. Demonstration projects that test alternative models of resettlement and use different approaches and timetables for economic adaptation may provide the information necessary to make a more informed decision.

Although there are limitations to the usefulness of the research, the recent studies contain findings that clarify some of the processes at work in refugee adaptation and allow for an examination of some of the basic premises underlying policy choices in the domestic assistance program. Since passage of the Refugee Act, a number of policies aimed at achieving these objectives have been promulgated, including:

- Cash assistance is conditioned on registration with an appropriate agency providing employment services (a provision that waived this requirement for refugees in the United States for 60 days or less has been repealed);
- States have been required to use 85 percent of their social service funds for services that are directly related to employment;
- Language training, cultural orientation and pre-employment training are now provided overseas to give refugees a headstart;
- Areas with large concentrations of welfare dependent refugees have been given targeted assistance grants aimed at stimulating employment among this population;
- The Office of Refugee Resettlement has provided special support for the development of Mutual Assistance Associations;
- Congress mandated implementation of demonstration projects to test alternative cash and medical assistance programs to determine if disincentives to employment inherent in the current welfare system can be removed; and
- ORR, the Bureau for Refugee Programs and voluntary resettlement agencies have developed placement policies aimed at limiting resettlement of refugees in areas of high impact.

These policies emanate from several premises regarding refugee resettlement. They include the beliefs that:

- services provided to refugees contribute positively to economic self-sufficiency;
- public welfare acts as a disincentive to economic self-sufficiency;
- refugee self-help groups play an important role in refugee adjustment;
- refugee dispersal aids effective resettlement and minimizes state and local negative impacts; and
- refugees represent a net negative impact on states and localities that should be offset by dollar-for-dollar reimbursement of their costs by the federal government.

Recent research studies have focussed on each of these basic underlying premises of refugee resettlement policy. The implications of this research regarding these points are discussed below.

Assumption: Services provided to refugees positively contribute to economic self-sufficiency for refugees.

As noted above, the most straightforward analysis that can be done of refugee self-sufficiency focusses on the personal characteristics of the refugees. Most studies have examined, in some detail, the relative impacts of demographic characteristics, previous education and occupation, and current proficiencies. In a far less detailed way, programmatic influences have also been examined, including use of language training and employment services and state welfare benefits and eligibility requirements.

Generally, the personal characteristics of refugees upon arrival and their demographic characteristics, including household size, are found to be stronger predictors of economic adaptation than either their current proficiencies (in English, for example) or the services they have used. In fact, the service programs that have been established to assist refugees, whether sponsorship models, employment services or language training, appear to have only a marginal impact on economic self-sufficiency.

There are a number of possible explanations for these consistent findings, some related to the research itself and others pertaining to the process of adaptation, the nature and quality of services, and the effects of the public assistance system.*

Economic adaptation may be a process that unfolds as it does, regardless of whether services are available or not. Some support for this theory comes from a comparison of refugee patterns of adaptation and those of other immigrants. The income curve exhibited by refugees is very similar to the immigrant pattern. Immigrants tend to have incomes that are well below U.S. averages upon arrival, but over time their earnings meet and then exceed those of other U.S. residents. Although it may take longer for some refugees, particularly those with little previous education, to follow this pattern, they are on the same course.

Some of the explanation for the marginality of services may reside in inadequacies in the service delivery system itself. First, the research has shown that employment services tend to be used by refugees who have the same characteristics that are found to influence employment rates positively: those who speak some English on arrival, those with better education and those with transferable skills. It appears that employment services, as they now function, best assist those who would be most likely to find jobs without assistance. They are generally not targeted on the harder-to-place refugees (for example, older refugees, secondary wage earners, those with fewer transferable skills). The Office of Refugee Resettlement and state governments should take steps to ensure that these refugees have adequate access to employment services.

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*With regard to the research studies, methodological problems may have limited their usefulness in examining the relationship between programs and self-sufficiency. The designs of the studies of refugee economic adaptation may be inadequate to measure accurately the impact of service utilization. Generally, questions about services are asked as yes/no questions: Has the refugee received employment services? Has the refugee been enrolled in a language training program? At most, questions are asked about the number of hours a refugee has been enrolled in a particular training program. These questions tell the researcher little about the quality or intensity of the services, and so make it difficult to assess the effects of the service on future outcomes. Moreover, there has been no evaluation, to date, that has made a detailed examination of the efficacy of employment services funded through refugee program funds. More information is thus needed about the effectiveness of various models for stimulating employment for refugees of different background characteristics.

Second, the services may appear to be marginal because they are not effective in accomplishing what is being measured—economic self-sufficiency—although they may be effective in other respects. For example, employment services are not often credited as a source of jobs for refugees, but the primary focus of many employment services is to teach refugees to find their own jobs. Language training is another example. Research has shown training programs to be effective in teaching refugees English, which is, of course, their primary reason for being. Yet, effectively teaching refugees English may not lead to economic self-sufficiency.

Social services may also appear marginal because of the type of services that are provided. Some needed services are not generally offered. For example, the research indicates that most refugee households need more than one employed person to pull themselves out of dependency. This finding would argue for day care facilities to permit more mothers to enter the labor force. In a similar vein, research shows that refugees residing in households with large numbers of dependent children are less likely to be self-sufficient or to find employment that pulls them out of poverty. These findings would indicate that family planning programs could have a beneficial impact on refugee self-sufficiency.

An even more alarming explanation of the lack of relationship between service use and economic adjustment may lie in the quality of services. Service utilization may have a marginal effect on self-sufficiency because the services themselves are poorly designed or poorly implemented. There is impressionistic data questioning the quality of many service programs. A recent study on case management noted that many service plans were standardized and repetitive (Lewin and Associates, et al: 1985). Case managers were often not aware of the broad range of services available within their jurisdictions. A rcent study of Hmong resettlement described language training programs as being so confusing that students got little out of them (NWREL, Hmong Resettlement Study, 1985).

Responsibility for poor quality of some services rests, in part, with federal and state policies. Little training and technical assistance is currently funded in the refugee program; performance standards have not been routinely developed; monitoring has often been *pro forma*, with little examination of quality; and funding has been erratic, causing disruptions in service continuities and difficulty in long-range planning. In addition, salaries are low and staff burn-out is not uncommon. Given the level of funding currently expended on services for refugees, steps should be taken to improve quality of services and to identify areas in which services are likely to make a difference in refugee outcomes.

A third explanation for the relatively poor showing of service interventions in stimulating economic self-sufficiency may be found in the effects of public assistance policy. The capacity of service providers—particularly voluntary resettlement agencies and employment services—to influence the employment patterns of their clients is, to some extent, determined by the availability of welfare. As will be discussed in the next section, the welfare system has been shown to create employment disincentives. It is possible that service utilization is sufficiently offset by the work disincentives of welfare to cancel out the beneficial impacts of the service programs.

Assumption: Public welfare acts as a disincentive to economic self-sufficiency.

No policy issue has been more debated than the impact on refugee adaptation—and, relatedly, U.S. costs—of using public assistance as the major form of transitional income support for refugees. Four major concerns about the welfare system have been raised: 1) the benefit levels; 2) limitations on earned income and work hours; 3) bureaucratic inefficiencies in the work registration program, WIN; and 4) work disincentives in the Medicaid system.

Clearly, welfare serves as a substitute for or addition to employment in states where public assistance benefits provide for a larger income, given household size, than a minimum wage job does. Every major research report has shown that refugees who live in states with generous welfare benefits are more likely to be receiving public assistance than those that live in states with more restrictive provisions.

These findings must be interpreted with caution, however. Do they mean that welfare serves as a disincentive to self-sufficiency, or do the generous policies of some states serve as a "safety net" for refugees throughout the country? There has been considerable secondary migration from states with restrictive policies into states with generous ones. It may well be that refugees who are able to find jobs stay where they are initially resettled and those who are unable to become self-sufficient relocate, thereby inflating the utilization rates of their new states.

Nevertheless, there are some clear work disincentives in federal and state welfare policies. The work disincentive effects of welfare are generally to be found in provisions pertaining to all AFDC recipients, not just refugees. Changes enacted several years ago have made it more difficult for welfare recipients to use welfare as a supplement to work. In many states, the real frustration is with welfare guidelines, particularly for the unemployed parent program of AFDC, that force refugees to choose between working more than 100 hours and losing their welfare benefits or remaining unemployed and collecting the full assistance grant. Even refugees with transferable skills are unlikely to find employment that pays significantly more than minimum wage. Moreover, low salaries are likely to continue for some time. Research shows that household incomes increase with multiple wage earners, not advances in wages. Therefore, limitations on the number of hours that members of a household can work and still receive supplemental assistance are likely to reduce incentives to take jobs.

Also of concern are referrals of AFDC clients into the WIN program, which has generally been unable to provide appropriate services for refugees. Many WIN clients are placed in an "unassigned pool," where they are required to do little in the way of job search activities. Finally, the links between cash and medical assistance eligibility requirements are believed to serve as a work disincentive.

It is because of these inadequacies in policy and implementation that several states are considering demonstration projects that will transfer refugee welfare caseloads out of AFDC and into Refugee Cash Assistance or create new cash and medical assistance programs. These various initiatives would permit a waiver of the 100 hour limitation on employment, thereby allowing refugees to gain work experience while receiving supplemental benefits if they remain income eligible. Also, refugees will be required to register with employment services that are specially tailored to their needs. The results of these demonstration efforts need to be carefully assessed.

Assumption: Refugee self-help groups play an important role in refugee adaptation.

The informal support systems that have evolved within the refugee community have been very important in the achievement of self-sufficiency. Most refugees find jobs through their relatives and friends. The most effective route to self-sufficiency is living in a household with several employable adults who are able to contribute to household living. The ethnic community also provides intangible support that facilitates the social, cultural and emotional adjustment of refugees.

Whether what informal support systems are doing for refugees can be captured in an organized way in formal institutions is another issue. The future of refugee adjustment is, in large part, dependent on the development of these infrastructures. Refugee communities are now trying to build viable, effective support structures and networks that will assist refugees over the long-term. Of particular concern is the development of service organizations that will be able to assist refugees when special eligibility for refugee programs is no longer available.

Careful attention must be paid to the development of these institutions. In particular, their needs for technical assistance, resource development and connections with mainstream U.S. institutions must be addressed. Also needed are better mechanisms through which refugees can be involved in decision-making processes at both the federal and state level. Policy directions that would impede the building of viable ethnic structures, such as placement policy that emphasizes dispersal at the possible expense of community development (see below), should be carefully assessed, keeping in mind the long-term needs of the refugees.

Assumption: Refugee dispersal aids effective resettlement and avoids undue burdens on states and localities.

The examination of the state-of-information regarding the residency patterns and secondary migration of refugees raises several policy questions and issues. The Indochinese have been more dispersed throughout the country than any other immigrant group about which there is comparable data. Further, efforts to balance the demands of family reunification and the desire to avoid further impacts in areas with high concentrations have been largely successful. Even prior to implementation of current placement policy (in fact, with the start of the Khmer Guided Placement Program and voluntary efforts on the part of the sponsoring agencies), the resettlement of refugees in areas with large concentrations of refugees had been reduced.

Interestingly, the greater concentration of other refugee populations has led to far less concern about placement policy than has the relatively more dispersed distribution of the Indochinese. Several reasons for this come to mind. First, refugees from most other nations have arrived in far fewer numbers. Large percentages of these groups have not necessarily translated into large refugee communities. For example, the 35 to 40 percent of the Indochinese population living in California equal about 250,000 people at this point. On the other hand, 100 percent of the Ethiopian refugees in the United States equals only about 10,000 persons. Even if all of them settle in one state, they will account for a fraction of the number of Indochinese. That overall numbers play a part is evident in the fact that the other refugee group that has evoked considerable concern with regard to placements are the Cuban refugees and more recently Cuban-Haitian entrants. Some 800,000 Cubans have entered the United States since 1960, and their concentrations in Miami and a few other areas has provoked criticism about placement policy.

Overall numbers, however, are not the sole explanation. There are several other immigrant groups that have settled in particular places in roughly the same numbers over the same period of time as have the Indochinese and Cubans. For example, over 300,000 Filipinos are estimated to have entered the United States between 1975 and 1982; 46.4 percent, or close to 150,000 indicated that they intended to reside in

California—a number that is identical to the number of Indochinese placed in California during the same period. (Neither figure includes secondary migration into or out of the state, and therefore, neither indicates numbers actually resident in California.)

The explanation for the particular interest in the placement patterns of the Indochinese may rest in the circumstances of their resettlement and adjustment to U.S. life. The Indochinese, unlike several of the other refugee groups, had no existing ethnic community in the United States upon their arrival in 1975. Therefore, their arrival was not cushioned by the activities of persons who had already established themselves in their U.S. communities. The Indochinese were truly newcomers and, thus, stood out all the more.

Further, the utilization of cash assistance and other service programs by the Indochinese, in combination with their absolute numbers, has made their presence in U.S. communities very apparent. The circumstances under which they fled Southeast Asia caused considerable attention to be paid to them as well, and not all of this attention was positively disposed towards the refugees. And, finally, the often traumatic circumstances under which they arrived in specific locations (particularly when proper notice had not been given of their arrival) led to community tensions and resentment that the refugees had been placed there.

If this analysis is true, it may be that the process used in arriving at placement decisions, including the consultation that takes place between sponsoring agencies and state and local officials, may be more important than the actual outcomes of placement in terms of the dispersal or concentration of refugees. This point is important because efforts to disperse refugees, though they have been successful in some cases, may be at odds with the preferences of the refugees themselves and may even undermine the efforts of refugees to become self-sufficient.

The relationship between refugee concentrations and self-sufficiency is an elusive factor in resettlement and one that is hard to prove. Whether adjustment is more rapidly attained within or outside of large ethnic communities is a question open to debate. It remains, however, that many immigrant groups have been highly concentrated in a few locations and have also rapidly attained economic success. More research is needed to determine if there is a cause and effect relationship at work.

The relationship between initial placement decisions and secondary migration is much easier to explain and document. Refugees generally prefer to be placed with other members of their nationality or ethnic group. Dispersal often means that this cannot happen, and some number of refugees are settled where they do not wish to be. If this happens, significant levels of secondary migration are likely to occur. As we have seen, 45 percent of the 1975 Indochinese arrivals moved to another state, and living in other-than-the-state-of-choice was the best predictor of the propensity to move. Since secondary migration occurs outside of official channels, and therefore little advance notice or preparations can be made, the arrival of refugees through this route is likely to cause greater dislocations than is true of initial placements. Secondary migration is therefore more likely to lead to the type of community tensions and resentments described above, thereby aggravating feelings that adverse impacts accompany refugee resettlement.

But even here the examination of the pattern of secondary migration indicates that both the phenomenon itself and its result are likely to be short-lived. If previous experience is a guide, we can expect, in the years to come, growing geographic stability among recent refugees to the United States. With increased employment and the establishment of social and other ties to their new communities, the degree of secondary migration exhibited by today's refugees is likely to draw closer to those of other U.S. residents. Certainly the pattern of movement—that is, towards the South and West—they have exhibited already puts them into the American mainstream.

Assumption: Refugees represent a net negative impact on states and localities that should be offset by dollar-for-dollar reimbursement of costs.

The impacts of refugee resettlement, as we have seen, are complex and difficult to calculate. A typical approach has been to define impact in a static, negative manner. Attention is paid to job displacement without equivalent analysis of job creation effects of resettlement. State and local costs are seen as any expenditure on behalf of refugees that is not reimbursed by the federal government, on a dollar-for-dollar basis, in the year in which the expense is incurred. Refugee tax payments are ignored altogether.

This approach masks the complexity of the situation. First, impacts may be positive or negative. Refugees cause state and local expenditures but they also bring federal funds into the area. Moreover, refugees themselves become employed, contributing members of society who benefit others through their tax payments and income-generating activities.

Second, federal funding for resettlement means more than reimbursement of incurred expenses. As has been shown here, the federal funds are used to purchase goods, employ staff and, ultimately, enter the state and local coffers through real estate taxes, sales taxes and the income taxes paid by both refugees and the service providers who assist them.

Third, the net gain or loss from the presence of refugees must take into account a variety of factors. At a minimum, the equation for assessing costs of refugee resettlement should reflect the net difference between federal funds and taxes generated by the presence of refugees, on the one hand, and state and local costs on the other.

Fourth, concerns about negative financial impacts may be masking concerns about social, cultural or labor market impacts. Reimbursement will not, in and of itself, offset these other concerns. On the other hand, the federal funds may make the presence of refugees more palatable.

Fifth, the financial impact of resettlement varies from year to year and from location to location. In part, the impacts will depend on the availability within state or localities of programs which can be accessed by refugees who are no longer eligible for federally-funded programs. Most states and localities will experience short-term positive impacts because federal funds and tax revenues generated by refugees and the refugee program during the first few years exceed the costs incurred by the state. Some of these states may, in the middle-term, experience negative impacts, because large numbers of refugees, after federal reimbursement is no longer available, continue to utilize services. At this stage, federal funds may not offset costs. But, if the pattern that has already been seen in the Southeast Asian population continues, most areas should see long-term benefits deriving from the presence of refugees, as the tax payments of refugees exceed the costs associated with providing services to them.

CONCLUSION

The research examined in this report has addressed basic issues regarding refugee resettlement: To what extent have refugees become economically self-sufficient? Have programs that serve refugees been effective in assisting them to become self-sufficient? What are the positive and negative impacts of refugee resettlement? What is the role of the refugee community in assisting its own members?

For the most part, the research provides good news for those concerned with the future of this country's long-standing tradition—providing refuge to the world's persecuted. Refugees in this country are moving inexorably towards economic self-sufficiency; refugees' English language proficiency increases with time in the country; and the development of refugee organizations bodes well for the future of these newcomers.

There are, nevertheless, challenges ahead. It is well to remember that refugee adaptation is a process and, at times, can be a lengthy and difficult one for both the refugees and the communities in which they live. While the research shows there is much to celebrate in the achievements of the refugees, there is still much to accomplish in the refugee program. The research indicates that refugee adaptation, to some extent, occurs despite—not because of—programmatic and policy interventions on their behalf. The refugee service delivery system needs improvement and the employment disincentives of the public welfare system must be addressed.

To conclude, refugee resettlement is a constantly changing process, one which requires substantial flexibility to address new issues. During the past five years, the United States has made substantial progress in identifying problems related to refugee resettlement, exploring alternatives and implementing new programs. As noted above, the years ahead will present their own challenges. The research conducted during the past few years should help policymakers and program implementors find new solutions.

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Mr. STOKES. Thank you very much, Ms. Kretzmann. You have done an excellent job.

We also deem it a real pleasure to have your distinguished representative here.

Mr. VENTO. Thank you, Mr. Chairman.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

ALFRED J. BAUMEISTER, VANDERBILT UNIVERSITY, AMERICAN ASSOCIATION ON MENTAL DEFICIENCY; AMERICAN ACADEMY OF MENTAL RETARDATION; AMERICAN PSYCHOLOGICAL ASSOCIATION

Mr. STOKES. We will now hear from Dr. Baumeister.

Mr. BAUMEISTER. My name is Al Baumeister, Director of the John F. Kennedy Center at Vanderbilt University, one of the 12 National Mental Retardation Research Centers. I represent the American Association on Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association.

We are grateful for the opportunity to share our views concerning Federal support, through NICHD, for research on mental retardation and related disabilities.

Mental retardation is a lifelong disability with social, psychological and biological causes. The principal manifestations are sub-average intelligence, significant impairments to learning, and to social and physical development, and diminished ability to live independently.

Over 200 different causes are associated with mental retardation, including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of teratogens, accidents, and other untoward circumstances that affect development, such as poverty, undernutrition, and lack of adequate psychological and social stimulation.

But we must emphasize that even in many of those cases in which we have some knowledge as to cause, we know precious little about how to prevent or cure.

The human and financial costs to society of mental retardation are staggering. No other human affliction creates so much suffering, for so long, and at such great cost to the individual, the family, the community, and our Nation.

There are approximately 6,600,000 retarded persons in the United States today and about one out of every six or seven families is directly affected.

To provide care and habilitation to the 130,000 retarded persons who reside in public institutions, we will spend over $4,500,000,000 this year. The average cost is more than $1,000,000 over the lifetime of each severely retarded individual. In 1984, the average rate across this country to care for a retarded person in an institution exceeded $100 per day.

The cost of education of a retarded child in the public schools is several times that of a non-retarded child. The variety of special programs in the community represents an enormous outlay as well, also now running about $4,500,000,000 annually, and increasing.

We must remember that mental retardation and the other developmental disabilities, if uncorrected, typically persist over a lifetime and there there are now many thousands of babies who will never have a chance, for even part of their lives, to share in the ordinary opportunities and challenges that we here enjoy.

Because the Congress has responded to the need, we have made enormous scientific progress over the past two decades toward the goals of prevention and amelioration of mental retardation. Much of this knowledge has been put into practice with outstanding results.

For example, we now understand the biochemistry underlying some specific genetic disorders and are now able to create medical and environmental conditions where people who only two decades ago would have been profoundly retarded are now able to live normal lives.

More importantly, studies of behavior and social processes have enabled us to develop effective educationally based procedures that ameliorate many of the learning and behavior problems associated with mental retardation.

We have also learned a great deal more about causes of mental retardation, knowledge that can have enormous significant public policy implications.

For instance, public policy has followed from the empirical demonstration that exposure to lead can cause biological and behavioral risks ranging from very severe to mild.

Similarly, we now have convincing experimental and descriptive data showing that alcohol and other drugs are teratogens that can have devastating effects on the developing fetus.

Over the past few years, a variety of exciting new behavioral and biomedical concepts and techniques have been incorporated into the study of mental retardation, such as the role of peptides and neurotransmitters in the functioning of the nervous system, sophisticated quantitative techniques for the study of neuropathology and neuroanatomy, the introduction of new cytogenetic procedures, the discovery of new methods for analysis of plasticity of behavioral development, improved understanding of how environments and biology interact, and new methods for promoting generalized learning and transfer of skills from one context to another.

Yet, we cannot become complacent. Despite advances in our understanding of mental retardation, and therefore in our ability to intervene effectively, the truth is that in most cases, we do not know what causes the retardation, or how to prevent it. One fact should be made clear: Mental retardation in most cases cannot be traced to a single specific biomedical cause.

Between 70 and 80 percent of the cases are linked to psychosocial disadvantage. In 1984, 14.4 percent of our population, including 21 percent of our children were below the poverty line.

But, as you are aware, minority groups are differentially represented. According to the government's own 1984 data, 46 percent of black children and 39 percent of Hispanic children lived in poverty.

But consider another factor. Whereas poverty among the elderly was recently a major social problem, these Americans now enjoy a better quality of life than ever. Poverty has virtually disappeared among the elderly; but there is still age bias associated with poverty and it is the children who are victims.

Consider the 1984 data for poverty rates: 24 percent amount preschool children; 20.3 percent among school-age children: 11.7 percent among adults, non-elderly; 12.4 percent among the elderly.

Poverty is not a wholesome condition for rearing children. Mental retardation does not cause poverty, but poverty contributes to mental retardation. Much more research must be addressed to this most fundamental issue.

Why is socioeconomic status associated with mental retardation and emotional disturbance? What are the implications for prevention? These are important questions, ones that have been addressed before, but not systematically and intensively, never with an adequate base of support. Their resolution is anything but clear.

One fact emerges from an analysis of the relevant literature. Environment, including family background, is a more significant role than biomedical factors in determining developmental outcome.

While it is true that some retarded people suffer from identifiable neuropathology, the vast majority do not. The studies before us show that, except for severe handicaps at birth, dysfunctions as defined by the "New Morbidity" are more strongly predicted by family variables than by biological risk factors. Prevention strategies will have to be based upon environmental considerations.

The relatively high risk of mental retardation and psychiatric disorder in lower SES groups is best characterized by a transactional process in which certain children are psychologically and biologically vulnerable to environmental and social variations that predispose them to school, economic and social failure: The New Morbidity.

I can tell you something more about this relationship. The environments in which economically deprived children develop are less conducive to good physical, social and behavioral development than are the environments of children not so disadvantaged.

These differences are deep-rooted, fundamental, enduring and intergenerational, a fact that has not received sufficient attention and respect, either by researchers or practitioners.

As a group, mothers of such children are not so well nourished, they are smaller, and they received less nurturing care as children themselves. When they have their own children, they are younger, frequently teenagers, and they have children more often.

When she is pregnant, the general health of a woman at the low SES range will be poorer than that of a women who is better off, and her fetus will be exposed to greater risk of infection, intoxication and trauma.

Prenatal and general health care are less accessible to her, a condition that appears to be growing even more serious owing to recent cutbacks in health care programs.

Today, she is far less apt to be married than her richer sister and thus more vulnerable to a number of threats to good child-rearing practices.

Babies of such mothers, on the average, when they are born, are smaller for gestational age, are more likely to be premature, die more readily and more suddenly, are sicker in infancy, suffer a higher rate of accidents, and run a greater risk of neglect than children born into better circumstances.

Their mortality is excessively high at birth and beyond; their illnesses more frequent, more persistent, and more severe.

Their development is a function of maternal health, age, income level, education, habits, and social milieu. During the school years, nutrition may be inadequate, the children may miss school more frequently, and housing is frequently substandard.

They will present a higher rate of learning problems, behavior disturbances, allergies and speech difficulties. Such terrible problems will not yield to insular, simplistic and cosmetic solutions.

Yet, since 1974, commitment to mental retardation research has deteriorated. For more than 10 years, my colleagues and I have conducted various types of analyses of NICHD funding patterns, with particular reference to the status of mental retardation as a priority within NICHD.

On general and compelling conclusion emerging from these analyses is that funding for mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with 12 years ago.

In 1986 dollars, our research capability is less than half what it was in 1975. Attached is a table that shows a regular and continuing decline in relative support for mental retardation research, from 1972 to 1985. This table is based on the budget of the NICHD's Center for Research on Mothers and Children. This is the organizational unit that carries the NICHD obligation to support of mental retardation research.

In 1985, NICHD expended a total of $44,000,000 on research projects dealing with mental retardation, out of a budget of almost $310,000,000, about 14 percent.

We do not believe that this is a level of response consistent with either, A, Congressional intent in creating the NICHD; or, B, the severity of the problem of mental retardation in human and financial terms.

It is also evident that much of what is counted as "mental retardation" research is not relevant and that a large proportion of the Institute's budget is directed at basic biomedical and behavioral research that has little or no relation to solving problems of mental retardation or closely related disabilities.

The Congress must insist that the Institute demonstrate relevance of its support to the problem of mental retardation.

In 1985, NICHD obligations came to a total of $309,823,000. The 1986 appropriation for the Institute was $322,282,000, an increase of about $12,000,000, or 4 percent.

However, in 1986, subsequent to sequestering and revision, the actual amount was $307,000,000, a decrease from the previous year. Now, the Administration proposes a budget of $309,119,000 for NICHD, less than in 1985 and certainly substantially less than what Congress appropriated in 1986.

Through the magic of the Gramm-Rudman-Hollings bill, such reductions are possible, because the arithmetic is impeccable. This year, the average reduction in grants was 14 percent at NICHD. But cuts of this magnitude hurt American people—children, mothers, families—and the question must be raised: Is that what we intend by way of public policy?

Those I represent are distressed over these events that affect not only NICHD but all of NIH. This is not some arbitrary budgetary consideration that will merely inconvenience a few people.

Continued cutbacks of health research capabilities are shortsighted, ultimately very costly, and constitute a grievous disservice to millions of Americans whose health, well-being, and quality of life depend on this government to respond.

I have listed in my written statement a number of recommendations, and two of those I should like to mention here.

First, we urge the Congress to increase funding to NICHD from 307,000,000 in the current fiscal year to 376,700,000 in fiscal year 1987.

This is in contrast to the Administration request for 309,100,000.

Two, that Congress mandate that at least 25 percent of the extramural support of NICHD be for research directly relevant to mental retardation.

Also, that the Congress increase commitment to continuation of high-quality, pre and post-doctoral research training by increasing funds in this category by 10 percent.

We have recently completed a study, Mr. Chairman, that indicates that the average age of the contributing researchers to the literature has increased to 41. That is not ancient, but it represents a significant increase over the years, in the age of the scientific community that is contributing research, which means that somewhere along the line, there is going to be a shortfall of active researchers in this field.

And I thank you.

Mr. STOKES. I thank you.

[The information follows:]

Recommendations

We respectfully encourage the Congress to increase appropriations to NICHD to a level that, at the minimum, ensures the continuity of research and research training programs and at a level that begins to reduce the decline in funding for mental retardation research about which we spoke earlier. We believe that this can be done in two ways: First, the Congress should provide for an increment in the NICHD budget adequate to offset the cumulative effects of inflation and to accelerate the effort in mental retardation research. Second, and more specifically, you should specify that mental retardation research should be elevated as a priority.

My colleagues and I also request that some of the implications of the information presented in our comments be reflected in the narrative report. We believe that improvement of mental retardation services depends on excellent basic behavioral and biological research on prevention, early diagnosis and intervention, learning, and long-term care. Most important, because mental retardation is a constellation of behavioral phenomena with numerous biological and psychosocial causes, collaborative research programs incorporating behavioral and biological components should be fostered. We urge:

1. The Congress to increase funding to NICHD from $307 million in the current fiscal year to $376.7 million in fiscal year 1987, an increase of about 23%. This is in contrast to the Administration request for $309.1 million for fiscal year 1987.

2. The Congress to mandate that at least 25% of the extramural support of NICHD be for projects directly relevant to mental retardation.

3. That the Mental Retardation Research Centers be designated as a special item in the budget.

4. The Congress to express its commitment to the continuation of high-quality predoctoral and postdoctoral research training by increasing funds in this category by 10%.

5. That the Congress ask NICHD to demonstrate that the mental retardation research supported by that Institute is truly and directly relevant to prevention and treatment of mental retardation and associated disorders.

6. That funds be transferred from NIMH to NICHD to support research on people who have the dual problem of mental retardation and mental disturbance.

NICHD Trends in MR Funding*

(Millions of Dollars)

Year	Total CRMC Funds	Total CRMC-MR	MRDD	MRRC Core
1972	42,838,000	21,365,000	17,250,000	5,856,000
1973	41,971,000	21,330,000	16,642,000	6,533,000
1974	51,894,000	23,886,000	18,096,000	5,761,000
1975	55,094,000	25,420,000	18,884,000	5,672,000
1976	60,161,000	27,016,000	20,423,000	5,608,000
1977	64,979,000	28,419,000	21,434,000	6,166,000
1978	73,790,000	30,298,000	23,318,000	6,455,000
1979	102,492,000	35,321,000	28,121,000	6,759,000
1980	101,154,000	34,731,000	27,559,000	6,751,000
1981	106,055,000	32,997,000	26,969,000	6,623,000
1982	105,530,000	31,768,000	25,963,000	6,549,000
1983	123,346,000	35,270,000	29,306,000	7,343,000
1984	135,489,000	35,699,000	29,263,000	7,737,000
1985	157,727,000	44,329,000	36,365,000	9,298,000

Percents of Total CRMC

1972	50	40	13.7
1973	51	40	15.6
1974	46	35	11.1
1975	46	34	10.3
1976	45	34	9.3
1977	44	33	9.4
1978	41	32	8.7
1979	34	27	7.0
1980	34	27	6.7
1981	31	25	6.2
1982	30	25	6.2
1983	29	24	6.0
1984	26	22	5.7
1985	28	23	5.9

*Source of Data: NICHD, Office of Planning and Evaluation

CRMC = Center for Research on Mothers and Children

MR = Mental Retardation research

MRDD = Mental Retardation Branch in the CRMC

MRRC Core = Mental Retardation Research Centers (Public Law 88-164) core support

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

PRESTON J. GARRISON, DIRECTOR OF FEDERAL RELATIONS, NATIONAL MENTAL HEALTH ASSOCIATION

Mr. STOKES. Our next witness would be Mr. Preston J. Garrison.

Mr. GARRISON. Thank you for the opportunity to present my testimony.

Whenever the Mental Health Association comes before the members of this subcommittee and its staff, we always feel that we are coming before friends and fellow advocates on behalf of the mentally ill.

As the Executive Director of the National Mental Health Association, the Nation's broad-based volunteer citizens organization dedicated to the promotion of mental health, prevention of mental illness and to improve care and treatment for persons suffering from mental illness, I am truly aware of and grateful for the work that all this committee has done to inform the White House, the Congress and the voters of the importance of adequate funding for human services programs.

And that is true, even in times when limited resources and budget deficits make such a message that sometimes is an unpopular one. I am here today to urge the members of the subcommittee to continue to provide the unwavering leadership which is essential, if we are to make progress in improving what is still woefully inadequate system services available to citizens who suffer from a mental or emotional illness.

The challenges before us are clear. High-quality research into the causes of major mental illnesses and the development of effective interventions and treatment methodologies must be allowed to move forward.

Next Monday, the Association's National Commission on the Prevention of Mental, Emotional Disabilities will release its final report, and copies of that report will be delivered to the subcommittee.

The recommendations which are contained in that report clearly indicate that a reasoned yet aggressive prevention strategy in the field of mental and emotional disorders would pay tremendous dividends to the Nation, if coupled with the continued expansion of support for basic research.

Prevention efforts in a disability area which annually cost the Nation in excess of $54,000,000,000 can no longer be relegated to the bottom of the resource allocation barrel.

A recent survey identified a group of psychiatrically disabled young adults as having only a 5-percent full-time competitive employment rate, although 92 percent were high school graduates, and 50 percent had attended college.

To overcome this tragic loss of training and earning potential, psychiatric rehabilitation programs funded through the community support program at NIMH must be continued and expanded.

Proposed budgetary cutback and program eliminations in a number of other areas, including social security disability insurance, supplemental security income, vocational rehabilitation, education for handicapped children, medicaid, social services and housing, also represent major concerns for those of us who are advocates for people with mental and emotional disorders.

The concerns of the National Mental Health Association and its nationwide membership are detailed in our written testimony, which has been provided to the committee.

Our belief is that we as a Nation and as a government have a legitimate social responsibility to persons who suffer from mental disorders which reaches beyond simple shelter, symptom control, custodial care and social isolation, and we know that you share this belief with us.

You may also be assured of our support and the support of the growing constituency of people who are concerned with and are willing to speak out on behalf of persons with mental illnesses, families, mental health professionals, who are represented by the various organizations.

All of these people are willing to support your efforts and to ensure and to work with you to ensure that the Federal Government fulfills its share of that responsibility.

I thank you for this opportunity to speak to you.

Mr. STOKES. Thank you, Mr. Garrison.

[The statement of Mr. Garrison follows:]

National Mental Health Association

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Mrs. Jess (Betty Jo) Hay
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TESTIMONY SUBMITTED TO

THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
OF THE APPROPRIATIONS COMMITTEE
U.S. HOUSE OF REPRESENTATIVES

ON
FY 1987 APPROPRIATIONS FOR
NATIONAL INSTITUTE OF MENTAL HEALTH

BY

PRESTON J. GARRISON
NATIONAL EXECUTIVE DIRECTOR

NATIONAL MENTAL HEALTH ASSOCIATION

MAY 1, 1986

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SUMMARY OF NMHA RECOMMENDATIONS
for National Institute of Mental Health
(in $ millions)

	FY '86* Congressional Appropriation	FY '87 President's Budget	FY '87 NMHA Proposal
Research	214.0	194.9	272.0
Research Training	18.0	15.8	27.6
Clinical Training	20.0	0	26.0
Block Grant	490.0	490.0	576.0
State Planning	0	0	5.0
Community Support	12.5	0	20.0
Protection/ Advocacy	10.0	0	10.5
Direct Operations	34.7	31.7	34.1

* prior to Gramm-Rudman sequestration

I am Preston J. Garrison, Executive Director of the National Mental Health Association, a nationwide, volunteer organization dedicated to promoting mental health, preventing mental illness and improving the care and treatment of people with mental disabilities. We represent more than one million citizen members and volunteers concerned with all aspects of mental health and the spectrum of mental illnesses.

Let me begin by quoting from recent public statements which we believe deserve wide circulation because they convey so vividly the essence of the message we are here to present. The first speaker said, "We are all now beginning to understand that the bell tolls for each of us when another American is stricken with one of these dread mental diseases. I remain committed to the fact that you shouldn't be cutting in an area that you haven't even begun to fund right." The second speaker stated, "The budget as presented to us is devastating to the retarded child and his education, to the disabled young man and his being taught a profession, to the young person desiring a college education, to the disadvantaged youngster needing remedial courses, to the elderly and the afflicted as it relates to our research budgets and grants at the National Institutes of Health". The first speaker was Senator Domenici at the National Mental Health Association's annual meeting; the second, Senator Weicker in response to the Administration's budget presentation.

We are keenly aware of and grateful for all that this committee has done to inform the White House, the Congress and the voters of the importance of adequate funding for human service programs but we are deeply concerned that the message is not being heard in all quarters. We are not here to convince this committee that our nation has an ethical responsibility to respond to the human needs of those unable to care adequately for themselves. That would be a case of preaching to the converted. We are here to provide you with additional data to substantiate your requests and to tell you that the members of our Association will support your efforts to assure that those human needs are responded to.

Perhaps it would be helpful to start with some questions. Why, in all the furor and condemnation of international violence, is there so little consideration given to the violence of everyday living faced by the poor and handicapped of whom mentally disabled people represent a large number? Why is the President's support for significant increases in research funding this year limited to research which is khaki colored? Why are the programs and policies which produced the present deficit being protected while domestic programs, many of which have been through five years of reduced Federal outlays, are being targeted for still further cuts?

As advocates for people with mental disorders, we cannot and will not stand quietly by and accept the dictum that all human services must be cut in order to balance the budget. We urge you to continue to provide the leadership that allows high priority programs to grow. When you are asked for justification for your stand, we suggest you refer to a few of the exciting new developments in the field:

1. As the underlying causes of the major mental illnesses are in the process of being unravelled, research is also producing interventions and treatment methodologies which have been refined to the point where significant cost benefits are being realized. In example, before antidepressants were routinely utilized, each year saw 120,000 inpatient beds filled with depressed patients. That figure is down to 19,600 today as a direct result of the antidepressant medications which are proving to be highly effective for the majority of patients. This cutback in the use of inpatient beds saved $2 billion yearly in hospital costs.

These same medications are being used as alternatives to electroconvulsive therapy, formerly the treatment of choice for deeply depressed, frequently suicidal patients. It is estimated that these increasingly effective drugs have reduced to 35-40,000 from 500,000 the numbers of patients requiring ECT. Since the usual course of antidepressant treatment is 85% less costly than that of ECT, the savings in both public and private dollars as a result of these constantly improved drug interventions is obviously substantial. This is to say nothing of the obvious advantages which oral medications have over such invasive procedures as ECT.

2. Brain research is now being recognized as a vital link in understanding the mechanisms of many disease processes. The impact of psychoneurological factors on the exquisitely complex immune system is an area causing scientific excitement. It holds tremendous potential in many areas including that of providing new leads to the prevention and treatment of such diseases as cancer and AIDS. To cut back funding on this kind of research makes no sense socially, economically or scientifically.

3. Panic disorders and phobias have surfaced as the most frequently reported psychiatric disorder among women and the second most frequently reported among men, except for the 18-24 year old group. Many of its victims are completely housebound, crippled by the disease, non-productive and a financial burden to family and society. The use of new imaging techniques have documented differences in blood flow between right and left brain during attacks and have substantiated brain chemistry involvement.

Although some drug treatment has been previously available, side effects have limited extensive use. Successful research efforts are now underway to develop "designer drugs", medications with limited side effects, designed to treat very specific conditions. As a preliminary step, scientists are now refining a procedure to clone specific receptor sites and eventually produce a model to be used in developing drugs which will fit that receptor perfectly.

4. Imaging technology is also uncovering new information about schizophrenia relating to deficient frontal brain blood flow. Understanding how this deficiency relates to thought impairment in schizophrenics will be a major advance in combatting the disease.

5. A recent survey identified a group of psychiatrically disabled young adults with only a 5% full time, competitive employment rate even though 92% were high school graduates and 50% had attended college. To overcome this shocking waste of training and earning power, psychiatric rehabilitation programs have been designed and implemented for groups like this. These programs are showing marked success in returning formerly hospitalized people to the active work force and to independent living. In addition, the training of staff has been incorporated into the program and similar models are being set up around the country. The benefits of such services to both the economy and the individual are too obvious to need further comment.

6. The most recent study of the costs to society of mental illness put the figure at $54 billion. Even this astounding figure is considered low since the reports notes:

> Potentially, the largest component of economic cost from mental illness is that of reduced productivity .... These costs are potentially of the same magnitude as estimates of reduced productivity due to alcohol abuse. ($50.5 billion) Unfortunately, at the present time, the lack of good data makes it difficult to assess productivity impairments associated with diagnoses of mental illness.

Although I am here to speak primarily about the NIMH appropriation, no advocate can fail to react strongly to the President's recommendations dealing with a broad array of human services which have direct impact on the population about which we are most concerned. Among those programs which we are watching most closely are Social Security Disability Insurance and Supplemental Security Income, Vocational Rehabilitation, Education of Handicapped Children, Medicaid, Social Services and Housing.

The underfunding and cutbacks recommended in many of these programs are blatantly counterproductive and fiscally unsound. It is not only inhumane but also imprudent to attempt to reduce programs which have, as ultimate goals, the enhancement of human potential, the relief of suffering and the reduction of non-productive disabling conditions. The cost, both social and economic, of illness, disability, diminished productivity and crime far outweigh any short term fiscal gains which might be realized from reduced funding.

In example, the President's budget recommendations slashing funding for low income housing of all kinds, including dollars to fund community group homes for people with mental illnesses, will not reduce outlays. Rather, the costs will be compounded with the burden shifting to communities and states. Longer, costly hospitalizations will be necessary for lack of appropriate and less expensive alternatives. There will be burgeoning numbers of homeless people with chronic mental illnesses needing care on an emergency basis. We will see a growing reliance on jails, the legal and social service systems as an expedient, frequently repetitive and most often inappropriate way of responding to a community's need to do something - anything - with its homeless and sick.

Further erosion of mental health services dollars can be expected as states and cities look to replace lost Federal dollars. Since mental health needs are seldom as high on the agendas of state and local governments as roads and bridges, one does not have to be a prophet to recognize that mental health budgets are highly vulnerable. We hope this committee will take the lead in opposing reductions in funding which will take its toll on people most in need.

The choices that Congress has to make may be difficult but we cannot accept the argument that there are no options but to cut indiscriminately and across the board. We know there are many on this committee who reject that solution. We urge you to stand firm in your belief that better ways of closing the federal deficit gap must be found and we do not believe it makes sense to ask human services to bear the burden of additional cuts when loopholes in tax laws allow some corporations to get by without paying their fair share. We do not question the need for an adequate and modern defense capability but careless and wasteful spending that enriches defense contractors without improving our military strength cannot be allowed to continue.

You will find attached our recommendations for the FY 1987 budget. The $272 million research recommendation is a minimal figure when one takes into account the cost benefits which will accrue from increasing our understanding of brain function, behavior and the etiology of the mental illnesses. That these benefits are now recognized as spilling over into the understanding and treatment of what were seen as purely physical illnesses is an additional compelling factor supporting our request. To impede the growth of knowledge by cutting funding is false economy. Let us consider only one illness, Alzheimer's disease. It becomes obvious that the incidence will soar over the next decade given the projected growth of our elderly population. Unless and until cause and treatment can be determined, this disease alone will add millions to Medicare, Medicaid, SSI and numerous other social program costs.

We are asking for $27.6 million in research training and $26.0 million in clinical training funds. We appreciate the ongoing support which Congress has provided for clinical training despite Presidential proposals to terminate the program. There remain large unserved and underserved populations. Federal support for mental health professionals is still vital, especially in view of unanimous evidence that certain populations and geographic areas are underserved, including enormous numbers of senior citizens, children, jailed populations and geographic areas are underserved, including enormous numbers of senior citizens, children, jailed populations and chronically mentally ill living in the community for these groups. We endorse the Congress' continued direction of NIMH (through report language) to focus the program on these targeted areas. Studies by the General Accounting Office (GAO) and the NIMH indicate that where trainees obtain their education and work experience influences where they decide to practice.

Research trainees supported by NIMH have declined steadily at a time when the need for scientists, well trained in newly emerging fields, has grown tremendously. Without stable and adequate funding, there is every indication that research manpower will dwindle to an unacceptable level. If the present promise and pace of NIMH research is to be realized and maintained in the coming decades, we must work to assure the future availability of the research manpower upon whom the nation will depend for the success of that effort.

Our recommendation for reserach training is based on the current research opportunities and needs of the field, and is consistent with the recommendations made by the Institute of Medicine (IOM) in its 1985 report, "Personal Needs and Training for Biomedical and Behavioral Research." At NIMH, the number of research trainees supported has declined over the past six years from a high of 1,350 to a projected 751 under the Administration's FY '87 budget proposal. Our recommendation would support 1,200 research trainees at NIMH, a number consistent with the levels recommended in the IOM report.

The $576 million which we are proposing for the ADAMHA Block Grant and the $5 million for State Planning will help to continue the federal/state/local partnership necessary to coordinate and provide services for a broad population in need. A significant portion of the increased funds would be used by states to provide community mental health intervention services for people with prolonged mental illness who are homeless, including outreach services to locate this population both in the streets and in shelters. The alcohol and drug abuse monies would be used to support the basic service system and expand services to those underserved populations identified by the states and communities.

Our recommendation for coordinated state planning would enable the continuation of planning initiatives in 7 states and the funding of new planning initiatives in several more states. These initiatives, conducted at high levels of state government, specifically address coordinated interagency planning so as to more effectively provide the entire range of services required by people who are seriously mentally ill living in the community. In FY 1985, 7 states received initial funding for such planning initiatives. While such planning normally requires a 5-year time frame, the Administration's failure to request funding for this program has resulted in a policy decision that the 1985 awards made in 1986 will be one-year grants.

The NIMH Community Support Program and other Services Demonstrations, while small in total dollars, have proven to be highly successful. Demonstration projects have pointed the way to effectively handle many of the most difficult chronically ill individuals. Funds are used to stimulate better planning and coordination of state and local programs by providing technical assistance and community based service programs. Success is reflected in the increasing focus of state and local communities on the needs of these individuals, the substantial drop in hospitalization of the target population, the success of demonstration projects and the number of applications to NIMH which continue to exceed available resources.

Viable alternatives to rehospitalization, to the streets and to the jails are being identified and are proving to be practical and effective. We cannot dismantle a program which is helping states and communities find new solutions to caring for people who do not need and cannot use a hospital setting. The $20 million we are proposing to fund CSP will be a small investment for an expected excellent return.

The recommended amount is necessary: (a) to continue and to expand NIMH services research initiatives on problems of homeless people with chronic and other mental disorders and to continue local demonstration projects for providing services for this hard to reach group ($5 million); (b) to continue demonstration projects on the more effective use and coordination of services for elderly persons who suffer from serious mental disorders ($1 million); (c) to plan and initiate demonstration projects to coordinate services for people with mental disorders who are in the jail and hospital systems ($ 2 million); (d) to continue state-wide CSP initiatives for adults who have chronic mental illness ($4.5 million); (e) to continue and to expand the Children and Adolescent Service System Program (CASSP) for children with serious emotional problems (6.2 million); (f) to continue to conduct important services system research ($1.3 million). The need for more effective planning, development, coordination, outreach and evaluation of services is not only critical, it is mandatory.

Our final recommendation for $10.5 million to fund the Protection and Advocacy program reflects our description of MHA volunteers as community advocates of people with mental handicaps. As such, we know full well the problems of abuse and neglect which can and do develop in the range of facilities caring for these individuals. The present system of public oversight has not been adequate to remedy such shameful mistreatment.

Hearings conducted by Senator Weicker in 1983 and 1985 and a comprehensive study undertaken by the staff of this Subcommittee on the Handicapped uncovered a pattern of patient abuse and neglect in public psychiatric hospitals of our nation. Similar problems have been revealed in nursing homes and community facilities caring for persons with mental disorders.

Unfortunately, many of the residents of these institutions have been abandoned or have outlived their closest family members. Their well-being has become dependent, in part, on the availability of trained advocates, knowledgeable about the operations of institutions and the rights of residents, who can investigate and remedy through legal and other advocacy techniques situations of ~~gross~~ negligence and abuse.

We believe the Protection and Advocacy legislation agreed to by the House and Senate conferees (S. 974) will provide the necessary services and are therefore supporting funding at the full authorization level. The program provides funds on a formula basis to expand the existing state Protection and Advocacy (P&A) System for the developmentally disabled to investigate complaints of abuse and neglect affecting mentally ill people and to pursue administrative, legal and other appropriate remedies. The P&A System in each state must have an advisory board of persons expert in mental health issues, with a majority representation of people who have received or are receiving mental health services and their families.

Thank you for hearing our testimony. Mankind is having to choose between the wonders of science and its terrors and this nation is looking to its leaders to make those choices. We hope our testimony will be of help to you in reaching the difficult decisions you are being asked to make.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

DR. JERRY WIENER, PRESIDENT-ELECT, AMERICAN ACADEMY OF CHILD PSYCHIATRY

Mr. STOKES. Our next witness will be Dr. Jerry Wiener.

Dr. WIENER. Thank you, Mr. Stokes.

Let me begin by expressing my appreciation, not only for the opportunity to present the statement for the subcommittee, but for your patience and forbearance, being here with us at this hour.

I am Jerry Wiener, Chairman of the Department of Psychiatry at George Washington University, and President-elect of the American Academy of Child Psychiatry.

My purpose today is to urge members of the subcommittee to support programs within the National Institute of Mental Health that have direct influence on research and training effecting the diagnosis and treatment of children and adolescents with psychiatric disorders, including alcohol and substance abuse.

The American Academy of Child Psychiatry is a national, professional association of over 3,200 child psychiatrists. Its members are physicians who have completed an adult psychiatry residency and two years additional fellowship training in child psychiatry.

Child psychiatry is the medical discipline concerned with the prevention, diagnosis and treatment of developmental and psychiatric disorders in children, adolescents and families. These disorders include affective illness, attentional and learning disabilities, schizophrenia, substance abuse, eating disorders, suicide and conduct disturbances.

The Academy appreciates the past support of the subcommittee in recommending continued appropriations for NIMH clinical training, research, research training, and community support programs, especially considering that zero funding has been requested by or when significant decreases were part of the President's budgets.

The Academy recommends the following amounts for fiscal year 1987 for NIMH programs: For clinical training: $26,000,000; for intramural and extramural research, $272,000,000; for research training, $31,300,000; and for the Community Support Program, which includes the Child and Adolescent Service System Program, $20,000,000.

Each of these programs has contributed significantly to the understanding and treatment of childhood mental illnesses, yet the Administration has proposed no elimination of support for clinical training and for the Community Support Program, and bone-cutting reductions in research and research training.

The NIMH clinical training program is especially important for the continued support of child psychiatry manpower. When I last testified before this subcommittee in 1979, I recommended a funding level of $85,000,000 for clinical training; today, I recommended a level of $26,000,000, which is a modest increase over the $19,000,000 available in fiscal year 1986 after the sequestration.

The amounts have decreased, but the need for more child psychiatry trainees has not. The number of identified emotionally disturbed children continues to rise. Recent studies estimate the number of children in need of mental health services at 7 to 10,000,000, with 3,000,000 children chronically mentally ill.

The Administration proposes that, "because of past Federal support for clinical training, a shortage of mental health professionals no longer exists."

This is simply not accurate, especially for the profession of child psychiatry. In 1980, the Graduate Medical Education National Advisory Committee identified child psychiatry as the medical specialty in most severe shortage.

The committee's report carefully notes the projected requirements for child psychiatry in the coming years:

"The Modeling Panel in reviewing the data on child psychiatry recommended that a range of 8,000 to 10,000 child psychiatrists be required for 1990. This range represents a dramatic increase in the number of child psychiatrists projected for 1990, yet has been advanced as an achievable goal which does not address all of the large unmet mental health needs of children."

At the same time as there have been dramatic advances in our understanding and ability to diagnose and treat children and psychiatric illness, the number of child psychiatry trainees does not fill the number of vacancies available in the training program. The number of child psychiatric residents graduating over the next few years will barely replace the attrition.

128 approved child psychiatry training programs have a capacity to train 665 child psychiatrists, but only 537 residents are in these programs, and half of these residents will finish their programs next month.

In a 1985 survey of 96 child psychiatry training programs in medical schools, 84 percent indicated a need for additional faculty. 51 training programs have a total of 80 funded faculty vacancies.

These indications of the shortage of faculty and trainees mean fewer child psychiatrists available to provide adequate care to an already underserved and unserved number of children and adolescents with serious emotional disturbances.

Cost containment by eliminating clinical training funds is counterproductive for several reasons:

One, training programs serve the communities in which they exist. Child psychiatry trainees under supervision serve as consultants to the schools, the courts, the local health agencies, inpatient and outpatient units, guidance centers, pre-schools, retardation programs, neighborhood centers, adolescent homes, and special emergency units for child abuse, drug abuse, or family violence.

Two, a large component of child psychiatry services and training is outpatient rather than hospital-based. Support for outpatient-based training is traditionally difficult, and now, of course, there are increasing constraints on hospital-based funding for graduate medical education.

NIMH clinical training funds, even at the minimal amount of training. In addition, the continuing appropriation of clinical training funds is an important communication of recognition by the

Congress that the continuation of child psychiatry training is an important national resource and priority.

We know that the training is long and pay low, and that as disincentives arise to discourage entry into the profession, the future shortage of the professional manpower pool to care for children will result in the most costly alternative of all: Untreated children who become dependent, emotionally disturbed and dysfunctional adults.

Three, a final point is to commend the members for their past report language specifying that clinical training funds be spent for certain underserved populations, including children. Your concern has kept the needs of children in the spotlight.

These needs will not diminish in the near future. The increase in high-risk children due to low birth weight, premature birth, or failure to thrive; the dramatic increase in adolescent suicide and the persistence of destructive aggression are but a few stark reminders of the continuing need for the highest quality professional training for prevention and early intervention services.

Prevention of life-long emotional disorders is a budget goal as well as an appropriate policy for child and adolescent mental health.

So, I again urge you to continue to support the NIMH clinical training program in the 1987 budget at a level of $26,000,000. In doing so, I do not intend to imply that research, research training and the Community Support Programs are any less vital or of any lower priority.

These programs taken together are an interwoven true safety net for the future. I will submit the entirety of my testimony for the record regarding the need to support increases in the research and research training programs, as well as the Community Support Program with its Child and Adolescent Service System Program.

Thank you for this opportunity to testify. I will submit the remaining portion of my testimony to the record and will answer any questions that you have.

Thank you, Mr. Chairman.

Mr. STOKES. Thank you, Dr. Wiener. We appreciate very much your appearance.

THURSDAY, MAY 1, 1986.

ADAMHA

WITNESS

M. W. PERRINE, PROFESSOR OF PUBLIC HEALTH AND PROFESSOR OF SOCIO-MEDICAL SCIENCES, BOSTON UNIVERSITY SCHOOL OF PUBLIC HEALTH

Mr. STOKES. Our next witness will be Dr. M. W. Perrine.

Mr. PERRINE. May I modify the preferred pronunciation of my name, it rhymes with porcupine, Perrine.

Mr. STOKES. All right, you may proceed as you like.

Mr. PERRINE. Thank you, Mr. Chairman.

I would like to offer some testimony today in support of continued research on alcohol abuse and alcoholism.

I am Professor of Public Health and Socio-Medical Sciences at Boston University, Schools of Medicine, School of Public Health and also Director of the Alcohol Research Unit at the Boston University School of Public Health, and I have conducted research in the area of alcohol use and abuse for some 20 years, and take a little nip myself every once in a while, so I am not appearing as a recovering alcoholic or a teetotaler, but rather someone who considers himself a social drinker.

A more detailed summary of my testimony has been submitted, and I will summarize the main points which focus primarily on the problem of drunken driving.

Previous figures have testified to the enormity of the alcohol abuse problem in this country, costing us approximately 100,000 deaths each year, and approximately $116,000,000,000 lost each year.

Drunken driving, a subset of this alcohol abuse problem, it is one which can hit any one of us personally as we use the highways and the sidewalks in this country. We do not need to be a drinker to be affected by the drunken driving problem.

Thirdly, research on drunken driving is beginning to make progress, but slowly, due to the enormous complexity of working in this real world area in which so many individuals are involved, and which the enormous number of activities involve, two of which are of greatest importance and greatest frequency are driving on the one hand, and drinking on the other.

The fourth point I would like to address is the cost involved in analyzing this problem, because of the complexities, but because of this very importance we need more, not less, funding in support for research, which is beginning to make progress and beginning to develop effective means for targeting selective prevention measures.

And the final point, the costs of research in this major health problem are extremely small relative to the potential savings in lives, suffering and dollars, when compared to the cost of some other Federal activities, many of which do not have a similar potential for savings.

Regarding the first point, that alcohol abuse in fact costs this country not just money, but lives, of the order of 100,000 lives each year, we hear many statistics, and we have heard many today.

100,000 lives per year, roughly equivalent to losing everyone in a city of the size of New Haven, Connecticut in one year. I doubt that any one of us could sit down and name 100,000 people. Most of us, if put to the task, can only name through association, recognition, perhaps 2,000 individuals.

In terms of the dollars lost on this one problem due to voluntary behavior on the part of individuals who consume alcohol, if those costs were aggregated, we would not need a Gramm-Rudman-Hollings bill.

It comes through voluntary behavior on the part of the many citizens throughout the country, and using a substance readily available at supermarkets, drug stores and so forth.

We need to know more about the substance which is used for pleasure on the one hand, and which also causes misery and death on the other hand.

We need to support the promising scientific research in this area through the extramural research funding as well as the intramural research of the National Institute on Alcohol Abuse and Alcoholism, which was formally charged with addressing this problem, among others, only 15 years ago.

I would like to concentrate on drunken driving. Again, thinking in terms of the statistics, until recently, one could not talk about the Vietnam War and the toll there, in aggregate terms.

I was recently at the Vietnam Veterans' Memorial and was deeply touched by the somber simplicity of this monument to some 58,000 American men and women who died in that war over a period of 16 years.

I couldn't help thinking later that we may never have a memorial to the American men and women who are lost each year of the same order of magnitude, some 50,000 Americans lost each year on the highways.

That loss is approximately the same size as comparable to losing everyone living in Harlingen, Texas each year. I have made the analogy in my prepared remarks about the loss per day.

You can do all kinds of things with statistics. We are losing about 75 Americans a day, roughly equivalent to one major airline disaster every day for a year.

Yet, if one such disaster were unequivocally linked to terrorist activity, say, by the Libyan Government, one can only imagine the consequences in this present environment.

Yet, how much attention is given to similar losses, actual losses in this country to those on the highway? Have we adapted to adjusting our thinking to this? Is it simply because it has been with us for so long?

We overlook one important element, because it has been with us for all our waking hours and all our years of reading newspapers; namely, that the violence and death involved in drunken driving is equally random.

Look at the figures for a moment. We might think the deaths, that they are the drunken drivers themselves, this is not correct. Fifty percent of the deaths are from the drunken drivers themselves. Another 11 percent from drunken pedestrians and 20 percent from individuals who are riding with a drinking driver, and the remaining 17 percent are individuals who we call innocent victims.

They were not in the car with the drinking driver, passenger with drivers in other cars, and that represents about 4,000 random, innocent deaths in this country each year.

We talk about accidents as these individuals having died accidents. There are many of us who do not accept the concept of an accident because it implies a random event.

Drunken driving fatalities are not random events. I don't have time to go into the other complexities of the problem. I will skip rather to some of the progress which is currently being made in the area of drunken driving research.

We have determined, for example, that it is especially lethal for our youth, that drunken driving crashes are the leading cause of deaths among teenagers, and their deaths are three times higher than that of older Americans.

Is this due to the lack of experience in driving among the teenagers? Is it due to the lack of experience in drinking, or due to the lack of experience in driving after drinking, or some combination in these?

We are gradually making progress in analyzing these and being able to take some selected countermeasures on this particular group.

The great complexity of research on this real world problem of drunken driving causes it to be costly. Rather than reduce the amount of money being spent, as we approach some clarity and some understanding, and therefore some predictability and hopefully some control in this area, at this very time we are suffering a reduction in the amount of research grant money available through the extramural program of the National Institute on Alcohol Abuse and Alcoholism.

This research must be conducted in the field, where the problem is, not in the laboratory; with the drivers, the police and others knowledgeable about the problem.

My own research, for example, it is concerned with drunken driving, and by relative terms, it is expensive research, of the order of slightly over $400,000 a year, including $230,000 for direct costs, and about $190,000 for indirect costs.

The current study that I am involved in involves, consists of 90-minute interviews with some 3,000 drivers, and these represent individuals across the whole spectrum, from non-drinkers to convicted multiple drunk driving offenders.

Doing a bit of analysis, this ends up to be $80 per interviewed driver, which in those terms is relatively inexpensive, but we need large numbers of individuals in order to achieve statistical stability and statistical significance.

This $80, if converted to terms which many of our respondents understand is about 20 six-packs, or less than a week's supply for some we are interviewing.

The fiscal year 1987 appropriation as recommended in the President's request would further reduce the amount of field research possible by two mechanisms, one of which would be the cost containment recommended in the stabilization, and the other would be in attempting to set a cap or an average for individuals, individual research projects.

I would like to address briefly in conclusion these two points that would in effect stifle research in this area.

First of all, the policy of stabilizing the total number of grants, as proposed in the President's fiscal year 1987 budget, actually has a destabilizing effect on the number of new and competing grants, because the increase in the number of continuation grants will automatically reduce the number of new and competing grants.

The reason for this relationship is not obvious; it stems from the fact that from year to year, the number of new and competing grants available will vary as a function of the total number of continuation grants that the NIAAA is previously committed to funding in the subsequent years of multiyear grants.

Second, the policy of taking an average cost for a new or competing grant based upon the historical level and then providing a small increase to rise up to a new average cost in effect creates a shortfall.

The reason for this apparent paradox is that the historical level for NIAAA specifically, but for all national research institutes in general, has been substantially below the level approved by the National Advisory Council.

In 1985, the average grant cost was $114,000 at NIAAA, and that was 7 percent below the Council-approved level. With the increase provided by the President's fiscal year 1987 budget, the average cost would rise to $124,000, but that is approximately the amount that Council actually approved back in 1985.

Therefore, in fiscal year 1987, the NIAAA average grant cost would at approximately the cost level it should have been at back in 1985.

A further drawback to applying an average grant cost at that level is that the NIAAA would then not be able to change directions and/or to fund research grants that were more expensive due either to the quality of the research or to the area in which the research is being done.

The reason it would not be able to do so is because the NIAAA would be locked in to an average cost at the low level projected in the President's budget.

The fiscal year 1987 recommendation in the Professional Judgment Budget for alcohol research is $72,037,000. This proposal stands in contrast to the President's fiscal year 1987 request of $56,618,000 for alcohol research.

If adopted, the proposed Professional Judgment Budget would provide a 15-percent increase in the number of research grants supported by the NIAAA.

If adopted, this proposal should also be followed by scheduled increases of approximately the same magnitude, 15 percent, each year through 1990, in order to facilitate the necessary and appropriate growth in the number of grants funded annually.

This proposal would also provide for awarding 116 new and competing grants, rather than 74, at levels recommended by the peer review committees, the so-called Initial Review Groups.

Further, this proposal would also provide adequate funds to allow at least a small number of grants to be awarded with a larger average cost so that some of the important, but most costly projects could in fact be undertaken in the future.

As an active member of the American Psychological Association, I strongly urge support for the recommended appropriations of $272,000,000 for the National Institute of Mental Health and $90,000,000 for the National Institute on Drug Abuse, as well as support for the 1987 Coalition of Biomedical Research Support.

Five, in conclusion, the costs of research on drunken driving and other alcohol abuse are extremely small relative to the potential savings in lives, suffering and dollars, especially when compared to the costs of other Federal expenditures, many of which do not have a similar potential for such savings.

In view of the increased competition for decreasing Federal funds, some criteria should be available to aid in reaching rational criteria on the relative priorities for appropriations.

We submit that the potential number of American lives saved, the number of injuries prevented, and the number of dollars spared are very compelling criteria for this purpose.

Research on alcohol abuse in general and on drinking and driving in particular clearly meet these criteria. The potential for such savings in this major public health problem area is enormous.

One cannot help being struck by the juxtaposition of the costs for military equipment, which may or may not have potential for saving American lives, and the costs for research on alcohol abuse and alcoholism, from which 100,000 Americans are actually dying each year.

For example, one need only think of the relative costs of an F-16 fighter plane at $18,000,000 each, a Pershing II missile at $32,000,000 each, or an MX missile at $87,000,000 each in comparison to the total annual budget request for research on alcohol abuse and alcoholism of approximately $70,000,000.

I understand from my Senator's office that the Department of Defense budget requests 216 F-16 fighter planes, 1,000 Pershing II missiles, and 21 MX missiles for fiscal year 1987.

We should remember to keep in perspective that alcohol abuse is currently costing America nearly 100,000 lives each year, that about 25,000 of these deaths occur in alcohol-related highway crashes, and that of these latter, over 4,000 innocent Americans like you and me are killed each year in these alcohol-involved highway crashes.

The significance of this annual loss is relative, depending upon whether one reckons in the mega-dead of wars or in the recent departure of a loved one. But by any scale, this loss and its cause clearly represent a major public health problem in a civilized society.

Can we afford not to seek solutions through increasingly accurate knowledge and understanding of the exact role of alcohol?

Thank you, Mr. Chairman, members of the committee, for this opportunity to present this material.

Mr. Stokes. Thank you, Dr. Perrine, for your appearance.

[The statement of Mr. Perrine follows:]

M.W. Bud Perrine, Ph.D.
Professor of Public Health
Professor of Socio-Medical Sciences

Boston University
School of Public Health
School of Medicine

Budget Subject: Research Appropriation for the National Institute on Alcohol Abuse and Alcoholism

Testimony before the
Subcommittee on Labor, Health and Human Services and Education and Related Agencies Appropriations

Committee on Appropriations
House of Representatives

May 1, 1986
3:15pm

TESTIMONY IN SUPPORT OF THE RESEARCH APPROPRIATION FOR THE NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

My testimony today is being presented in support of research on alcohol abuse and alcoholism. I appear before this Subcommittee as a university professor and as a scientist who has specialized in alcohol studies for almost twenty years. I am currently Professor of Public Health and Professor of Socio-Medical Sciences at Boston University Schools of Medicine and Public Health. My training is in the area of experimental social psychology. A more detailed summary of my relevant background is submitted as an attachment to my testimony, for inclusion in the Record.

MAIN POINTS

In the course of my brief testimony, I would like to discuss the following five points.

1. Alcohol abuse represents an enormous social and economic cost to our nation, with a loss of nearly 100,000 lives and a cost of more than $116 billion each year.
2. Drunken driving is a major public health problem, one that can hit any one of us personally whenever we use the highways and sidewalks anywhere in our nation.
3. Research on drunken drivers is beginning to make progress, but slowly, due to the extraordinary complexity of the problem which is embedded in two of our most frequent activities: driving and drinking.
4. Due to the great complexity of this real-world problem, quality research is expensive, but we need a higher--not

lower--level of funding to continue progress and to develop effective means for targeting future prevention.

5. The costs of research on this major public health problem are extremely small relative to the potential savings in lives, suffering, and dollars, especially when compared to the costs of some other federal activities, many of which do not have a similar potential for such savings.

DISCUSSION

1. Alcohol abuse costs this nation dearly. The annual loss of about 100,000 lives represents losing the equivalent each year of almost all the residents of a medium-size city, such as New Haven, Connecticut. It also costs us more than $116 billion each year; if those dollars could be saved and aggregated, we would not need a Gramm-Rudman-Hollings Bill to fight the national deficit. And all this damage is due not to a natural disaster, war, or plague; rather, it stems from the behavior of ordinary citizens who voluntarily drink beverage alcohol (such as beer, wine, and liquor), legally and readily available throughout our nation in such respectable establishments as supermarkets, drugstores, restaurants, and hotels.

The prevalence of drinking, as well as the legality of beverage alcohol and its contribution as a source of tax revenues, raises a number of important questions. For example, what role does beverage alcohol play in our society, and what are the trade-offs involved in its use and abuse? What if beverage alcohol had not been used traditionally since prehistory, but rather had been introduced in the United States for the first time by the hippies and flower children of the 1960s; would it be legally and broadly available today? What is it about beverage alcohol that means gracious pleasure, relaxation, and celebration to so many of us, but brings disease, suffering, and even death to millions of other Americans--many of them innocent bystanders or long-suffering victims?

We need to know much more specifically about the actions of alcohol on the body, on the mind, and on behavior to begin developing and implementing effective and selective prevention measures that will permit the continued voluntary pleasures for so many, yet will avoid the consequent misery for others. To these ends, scientific inquiry and research are absolutely necessary; and the National Institute on Alcohol Abuse and Alcoholism is the specific federal agency officially charged with that mission (among others) when it was established just fifteen years ago.

2. Drunken driving is a major public health problem. Recently, for personal reasons, I visited the Vietnam War Memorial for the first time. I was very deeply touched by the sombre simplicity of this eloquent monument to the American men and women who died during the many years of the Vietnam War, numbering almost 57,000. Afterwards, I wondered if those who died in highway crashes would ever have any kind of memorial; they number almost 50,000 each year. That is comparable to

losing everyone living in a small city about the size of Harlingen, Texas. And approximately half of these, or 25,000 deaths, result from alcohol-involved crashes. That is comparable to losing everyone living in a community about the size of Chevy Chase, Maryland, each year.

Each day, 75 Americans are killed in alcohol-involved highway crashes. That is comparable to 365 major airline crashes each year. And if even 1 such airline crash could be linked unequivocally to terrorist actions by, say, Libyan nationals, what would be the international consequences at this point in our history? By contrast, how much federal attention is focused on the American deaths due to alcohol-involved highway crashes? I have not chosen the terrorism analogy to be sensational, but rather to use a timely problem of great national concern and one that has at least one element in common with alcohol-involved fatal crashes: random violence and death.

What categories of individuals die in alcohol-involved highway crashes? Only 52% are the alcohol-impaired drivers themselves, and another 11% are drinking pedestrians. Of the remaining victims, 20% are passengers in the drinking driver's vehicle, whereas 17% are passengers, drivers, or non-drinking pedestrians who were not in the drinking driver's vehicle. Thus, over 4,000 innocent victims are killed in alcohol-involved highway crashes every year, with another 5,000 victims killed because they were in the drinking driver's vehicle at the time of the crash. In terms of 4,000 innocent victims, then, that is roughly comparable to losing the Boston Celtics starters and their backups or the offensive team of the Dallas Cowboys every day because of being killed by drunken drivers. But the point of these collective examples is that any one of us here in this room or anywhere else in this nation could be killed by the random violence of a drunken driver crashing into us as we innocently use the highways or sidewalks throughout America.

The random violence of international terrorism is relatively new and is especially frightening because of its unpredictability. By contrast, the random violence through which thousands of innocent Americans are killed by drunken drivers each year is not new to us, but it is nevertheless relatively unpredictable. Have we simply adapted to having such deaths as part of the cost of using our highways and sidewalks because we have lived with this slow day-by-day loss for as long as we can remember? Do we shrug collectively and accept the deaths of these innocent victims as being the inevitable result of highway "accidents" which could be anyone's misfortune or bad luck?

Some of the researchers and policymakers concerned with drunken drivers and public health do not share the views in these rhetorical questions. Let me briefly outline the most important assumptions underlying a new programmatic line of research aimed at reducing the magnitude of the drunken driving problem. These basic premises are presented sequentially below, proceeding from the more general to the more specific:

a. Highway crashes constitute one of our largest public health problems in terms of annual losses, both human (44,600 deaths and 1,600,000 disabling injuries in 1983) and economic ($43.3 billion in 1983).

b. All crashes are not "accidents," i.e., are not random events. Certain factors are overrepresented in crashes; an understanding of these factors should lead to increased predictability and control.

c. Alcohol is involved in approximately 50% of fatal crashes; the more violent the crash, the more probable that alcohol was in fact involved--and the more probable that it was involved at high blood alcohol concentrations.

d. Many motorists drive after drinking, but only a very small proportion of them become involved in a crash. The fact that crashes are relatively rare events statistically is not a sufficient explanation.

e. Many of the differences between those motorists who drink and then crash and those who drink but do not crash are probably systematic and measurable.

f. Further, many of the differences between motorists who drive after no drinking, after moderate drinking, and after heavy drinking are also probably systematic and measurable.

g. These systematic differences should be specifiable in terms of "predisposing factors" or predictor variables in demographic, drinking pattern, driving history, life event, attitude, and personality domains.

h. The relevant populations and subpopulations at risk should be differentailly describable in terms of these predictor (or independent) variables.

i. By determining the relevant systematic differences in predictor/independent variables, it should also by possible to estimate a given driver's level of risk for an alcohol crash.

j. These individual risk levels should in turn be useful for developing more customized prevention, treatment, and sanction measures. They should be especially useful for the early identification, diagnosis, and referral of high-risk drinking drivers, as well as for predicting recidivism and alcohol program compliance and completion for those convicted of drunken driving.

The problem is exceedingly complex. It cannot be solved with slogans (for example, "Friends don't let friends drive drunk", "Stop drunk driving", etc.). It cannot be solved by the prohibition of alcohol, as in the Great Experiment. Thus, our only hope is based on achieving the three goals of science: increased understanding of the phenomenon, leading to increased prediction regarding the phenomenon, leading in turn to increased control of the problem. The key to understanding, the first link in this chain, is quality research focused on drinking drivers.

3. Research on drunken driving is making progress. However, the rate has been quite slow due in part to the extraordinary complexity of the phenomena and in part to the lack of predictable research funding that would in turn facilitate a coordinated systematic approach to the problem. Let me address

the complexity issue here, and postpone consideration of the funding issue to the next point.

Almost every American uses the highways, either as a driver or as a passenger. Most of us also use the sidewalks or roadsides. Just in terms of the sheer number of drivers in America, the magnitude and complexity of this problem area are overwhelming. And the vast majority of Americans also drink alcoholic beverages. And a large proportion of Americans drive after drinking, some after 1 or 2 drinks, some after 5 or 6 drinks, and some after 10, 20, or 30 drinks. Thus, there are an enormous number of possibly relevant variables and contributing factors in this problem area.

We have already determined age differences; for example, alcohol-involved crashes are the leading cause of death for teenagers (ages 15-19); and when alcohol is involved, the fatal crash rate of young drivers is three times that of older drivers. Thus, experience with driving, experience with drinking, and experience with driving after drinking are all possible components in understanding such age differences. Other factors possible associated with different crash rates among drinking drivers might well be differences in attitudes, differences in personality, differential sensitivity to alcohol actions on behavior, as well as even genetic predispositions to be able to tolerate alcohol effects. Recent research on some of these variables has been useful in differentiating among broad types of drinking drivers. Thus, there is ample reason to believe that further research along these lines will be productive in further refinement and differentiation among high-risk versus medium-risk versus low-risk drinking drivers.

4. The great complexity of research on this real-world problem of drunken driving causes it to be costly. However, we need a higher not a lower level of funding to assure continued progress and to develop effective means for selectively targeted prevention. The complex object of study is embedded in two of our most frequent activities, namely, driving and drinking. Valid conclusions about the interaction between these two frequent activities cannot be obtained by studying them in isolation or just in the laboratory. Rather, it is necessary to go out of the university, to go out into the field, to observe and inteview drinking drivers, and to work with the police and others involved with this problem in the real world.

The contributing factors and significant variables must be teased out painstakingly from the complexity of the whole problem. Furthermore, the more complex the phenomenon, the larger the number of subjects needed for adequate differentiation and for statistical significance. Field research that begins to address a major public health problem of this magnitude is much more costly than laboratory research on isolated variables (for example, alcohol effects upon skilled performance such as reaction time on a psychomotor task). Any attempt to force cost containment on such field research would therefore be both stifling and counterproductive. Ultimately, the nature of the problem drives the nature of the research -- and that should in turn determine the nature of the costs.

For example, my current research grant from NIAAA is concerned with drinking drivers and is relatively expensive at approximately $432,000 this year (namely, $237,000 for direct costs, and $195,000 for indirect costs). However, the current year of study involves conducting 90-minute interviews with almost 3,000 drivers including the full spectrum of drinkers. Using the total of all direct costs, that means an average cost of only about $80 per interviewed driver just for data collection. Or, in terms that many of our drunken driver respondents would understand, that cost per interviewed driver is comparable to 20 six-packs of beer, less than a one-week supply for some of our respondents. But, expensive as my type of field research may seem, it should be emphasized that both the research design and the budget were reviewed and highly recommended by the Initial Review Group (a committee of selected peer experts in this field) and were approved by the National Advisory Council of the NIAAA. These checks and balances of the grant process are crucial elements in fostering high quality creative research.[1]

If the FY 1987 research appropriation for the NIAAA is not increased as recommended by the Professional Judgment Budget, but rather is decreased as in the President's request, then the funds available for real-world field studies concerning drinking and driving will not be adequate to support meaningful research on this problem. If the appropriation is as restricted as in the

President's request, then the already small number of grants and specialists in this important public health research area would diminish further. Unfortunately, there are currently so few really dedicated and talented scientists in this area that we cannot afford to lose any at all. On the contrary, we desperately need to attract more new research talent to the alcohol abuse area in general and the drinking-and-driving area in particular. Indeed, because of the life-and-death significance of this public health problem, we need to attract some of the very best new scientific talent to alcohol research.

To provide research continuity and program predictability, we must resist cutting the NIAAA research appropriation in subsequent years. For example, we have experienced a 10% cut in our approved grant budgets last year and a further 4% cut this year; we face a possible 25% cut next year. With a cumulative reduction of almost 40% in our research budgets, it will become impossible to conduct the studies and analyze the data as scheduled and as necessary. Such massive cuts also cause staffing problems through reductions and uncertainties. But the main point is that, rather than reducing, we should be building; and we should be training new researchers in this crucial pubic health problem area.

Consequently, I strongly support the Professional Judgment Budget for the FY 1987 NIAAA appropriation and thus oppose the counterparts in the President's budget. Among other effects, adoption of the reduced appropriation as recommended in the

President's budget would permit the funding of only 74 new and competing grants, which is 26 fewer than the level of 100 appropriated by the Congress in FY 1985 and FY 1986; it would also require 16% cuts in the average costs of the new and competing grants. In the process, it would greatly reduce the flexibility the NIAAA needs in funding grants of varying magnitudes of cost and would lead us further toward the philosophy of cost containment, which under the President's request, would allow for an average annual total of only $124,000 per grant for both direct and indirect costs.

Two important points must be made in this regard. First, the policy of stabilizing the total number of grants, as proposed in the President's FY 1987 budget, actually has a destabilizing effect on the number of new and competing grants because the increase in the number of continuation grants will automatically reduce the number of new and competing grants. The reason for this relationship is not obvious; it stems from the fact that from year to year, the number of new and competing grants available will vary as a function of the total number of continuation grants that the NIAAA is previously committed to funding in the subsequent years of multi-year grants.

Second, the policy of taking an average cost for a new or competing grant based upon the historical level and then providing a small increase to rise up to a new average cost in effect creates a short-fall. The reason for this apparent paradox is that the historical level for NIAAA specifically (but for all national research institutes in general) has been substantially below the level approved by the National Advisory Council. In 1985, the average grant cost was $114,000 at NIAAA and that was 7% below the Council-approved level. With the increase provided by the President's FY 1987 budget, the average cost would rise to $124,000, but that is approximately the amount that Council actually approved back in 1985. Therefore, in FY 1987, the NIAAA average grant cost would be at approximately the cost level it should have been at back in 1985. A further drawback to applying an average grant cost at that level is that the NIAAA would then not be able to change directions and/or to fund research grants that were more expensive due either to the quality of the research or to the area in which the research is being done. The reason it would not be able to do so is because the NIAAA would be locked in to an average cost at the low level projected in the President's budget.

The FY 1987 recommendation in the Professional Judgement Budget for alcohol research is $72,037,000. This proposal stands in contrast to the President's FY 1987 request of $56,618,000 for alcohol research. If adopted, the proposed Professional Judgement Budget would provide a 15% increase in the number of research grants supported by the NIAAA. If adopted, this proposal should also be followed by scheduled increases of approximaely the same magnitude (15%) each year through 1990 in order to facilite the necessary and appropriate growth in the number of grants funded annually. This proposal would also provide for awarding 116 new and competing grants (rather than 74) at levels recommended by the peer review committees (the so-called, Initial Review Groups). Further, this proposal would also provide adequate funds to allow at least a small number of grants to be awarded with a larger average annual cost so that some of the important, but more costly projects could in fact be undertaken in the future.

As an active member of the American Psychological Association, I also strongly urge support for the recommended appropriations of $272,000,000 for the National Institute on Mental Health and $90,000,000 for the National Institute on Drug Abuse, as well as support for the 1987 Coalition of Bio-medical Research Support.

5. In conclusion, the costs of research on drunken driving and other alcohol abuse are extremely small relative to the potential savings in lives, suffering, and dollars, especially when compared to the costs of other federal expenditures, many of which do not have a similiar potential for such savings. In view of the increased competition for decreasing federal funds, some criteria should be available to aid in reaching rational decisions on the relative priorities for appropriations. We submit that the potential number of American lives saved, the number of injuries prevented, and the number of dollars spared are very compelling criteria for this purpose. Research on alcohol abuse in general and on drinking and driving in particular clearly meet these criteria. The potential for such

savings in this major public health problem area is enormous.

One cannot help being struck by the juxtaposition of the costs for military equipment, which may or may not have potential for saving American lives, and the costs for research on alcohol abuse and alcoholism -- from which 100,000 Americans are actually dying each year. For example, one need only think of the relative costs of an F16 fighter plane at $18,000,000 each, a Pershing II missile at $32,000,000 each, or an MX missile at $87,000,000 each in comparison to the total annual budget request for research on alcohol abuse and alcoholism of approximately $70,000,000. I understand from my Senator's office that the Department of Defense budget requests 216 F-16 fighter planes, 1,000 Pershing II missiles, and 21 MX missiles for FY 1987.

We should remember to keep in perspective that alcohol abuse is currently costing America nearly 100,000 lives each year, that about 25,000 of these deaths occur in alcohol-related highway crashes, and that of these latter, over 4,000 innocent Americans like you and me are killed each year in these alcohol-involved highway crashes. The significance of this annual loss is relative, depending upon whether one reckons in the mega-dead of wars or in the recent departure of a loved one. But by any scale, this loss and its cause clearly represent a major public health problem in a civilized society. Can we afford not to seek solutions through increasingly accurate knowledge and understanding of the exact role of alcohol?

FOOTNOTE

TESTIMONY IN SUPPORT OF THE RESEARCH APPROPRIATION FOR
THE NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM
M.W. Bud Perrine, Ph.D.

[1] The major alternative to the research grant is the research contract, as used by numerous federal agencies: in the area of alcohol and traffic safety, for example, it is used by the National Highway Traffic Safety Administration of the Department of Transportation. To obtain a research contract from a federal agency, the potential investigator simply submits a detailed work plan describing how he would conduct a study of the very specific topic specified in a "Request for Proposal" prepared and announced by the agency (a topic usually conceived and structured by one or two bureaucrats) and how much it would cost if he were to do so. The major weaknesses in this contract approach are: (1) the problem to be investigated is determined and phrased by a federal bureaucrat who may or may not have adequate research experience to structure such problems meaningfully; (2) the responses submitted to the federal agency by potential investigators -- or "bidders" -- are reviewed by this same bureaucrat, plus perhaps a few other bureaucrats in the same office; (3) worst of all, after the submitted proposals have been reviewed for research merit, the final decision on which of the surviving proposals will actually be awarded the contract is made by some accountant simply on the basis of the lowest bid to

do the research, i.e., the cheapest study possible among those available for consideration. There is no question that such a research contract will cost the federal government less money that a grant (all other things equal), but there is also no question that the creativity and quality of the contracted research and its findings will be much more limited. (If requested, I could provide numerous examples of differences between grant and contract research in this drunken driving problem area.)

The research grant process actually fosters scientific creativity through encouraging open competition of ideas and thus free enterprise. As such, the grant mechanism provides strong support for academic freedom. This feature of scientific enterprise in America is truly unique in the world, especially based upon my own research experience in Germany and in England. By contrast, the research contract stifles creativity by the individual scientist who must respond to a very specific problem as structured by some nameless/faceless bureaucrat. Further, the contract process allows a great amount of government control and intrusion into the research process, which further reduces free enterprise and constrains academic freedom.

BIOGRAPHICAL SKETCH

TESTIMONY IN SUPPORT OF THE RESEARCH APPROPRIATION FOR THE NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

M.W. Bud Perrine, Ph.D.

A brief outline of my relevant background in this area might provide a useful basis for evaluating my testimony. I am currently Professor of Public Health and Professor of Socio-Medical Sciences at Boston University Schools of Medicine and Public Health. My training is in the area of experimental social psychology and my degrees are in psychology (B.A. from the University of Connecticut, Ph.D. from Princeton University).

In 1968, I began my first alcohol research project as a young Assistant Professor at the University of Vermont. That project was primarily concerned with the role of alcohol in highway safety in terms of the behavioral and medical aspects involved. It was funded by the National Highway Traffic Safety Administration of the U.S. Department of Transportation. The results of that award-winning research have played a significant role in the design of subsequent investigations nationwide, as well as in the conceptualization and design of major countermeasures against drunken driving undertaken by the Department of Transportation, namely, the Alcohol Safety Action Program (ASAP) of the early 1970s. In fact, I was invited to be one of the major architects of the ASAP, which, under Congressional mandate, funded multi-year drunken driving countermeasure projects in 35 states and municipalities throughout the United States.

During the late 1960s and early 1970s, I conducted numerous studies on alcohol impairment of skilled performance (such as driving, flying, etc.) by means of controlled alcohol-dosage experiments, both in the laboratory and in instrumented cars driven on closed courses. These studies were funded over the years either by research contracts with the National Highway Traffic Safety Administration or by research grants from the National Institute on Alcohol Abuse and Alcoholism.

In more recent years, both in the United States and in Europe, I have focused increasingly on psycho-social and epidemiologic studies of drinking drivers, especially those arrested for driving under the influence of alcohol (DUI). Currently, I am conducting a large-scale research program which involves testing and in-depth interviews with four different but interdependent segments of the American drinking and driving public: (1) the general driving population, (2) the nocturnal driving population, (3) the convicted first DUI offender population, and (4) the convicted multiple DUI offender population. The results of this research program are expected to enable the development of much more effective means for preventing, deterring, and intervening in this major public health problem of driving after drinking. It should be noted that this research program is funded by a grant from the National Institute on Alcohol Abuse and Alcoholism.

Regarding other relevant professional activities, I am serving on the Steering Committee of the Congressionally-mandated investigation of "Alcohol-related Accidents in Recreational Boating" being conducted by the Transportation Research Board of the National Research Council, National Academy of Sciences, in cooperation with the U.S. Coast Guard. I am also serving as a member of the Planning Committee for the conference series on "Performance Guidelines Related to Alcohol and Drugs in the Transportation Industries" for the Alcohol Research Utilization System of the National Institute on Alcohol Abuse and Alcoholism and the National Institute on Drug Abuse. In recent years, I have also been serving as an invited peer reviewer of research grant applications submitted to the National Institute on Alcohol Abuse and Alcoholism. Also of relevance, I am a member of the Committee on Alcohol, Other Drugs, and Transportation recently formed by the Transportation Research Board of the National Research Council, National Academy of Sciences.

THURSDAY, MAY 1, 1986.

NIGMS

WITNESS

THOMAS E. THOMPSON, PROFESSOR OF BIOCHEMISTRY, UNIVERSITY OF VIRGINIA

Mr. STOKES. Our next witness will be Dr. Thomas E. Thompson. Dr. Thompson, I want to welcome you before the subcommittee, and you may proceed in any way you like.

Mr. THOMPSON. Thank you, Mr. Chairman.

I might say, I am Professor of Biochemistry at the University of Virginia.

Mr. Chairman and members of the committee, it is a great pleasure to be here today to testify on behalf of the National Institute of General Medical Sciences, NIGMS. As a working scientist who has benefited from the NIGMS programs, I am grateful for the opportunity to appear before you and present my views on this matter.

Over the years, this distinguished committee has shown time and again its commitment to improving and maintaining excellence in our country's biomedical research.

Just as importantly, this committee recognized the importance of insuring future generations of biomedical scientists and has actively promoted the training of students through grants and fellowships.

Mr. Chairman, it is infrequently that a scientist seeks the opportunity to testify before Congress. In these times of economic austerity, however, I feel compelled to come so that I may further impress upon you the urgency and importance of maintaining the non-categorical research programs at NIH, particularly those at the NIGMS.

Over the past 30 years, I have dedicated my scientific career to the study of biological processes at the molecular level. During this time, my research and that of my colleagues has helped us better understand an extremely important part of living things: The membrane that surrounds each cell.

Not so long ago, we only knew this membrane existed; today, we have come to realize the unique role it plays, not only as a barrier which preserves the integrity of the cell, but also as an active participant in immune responses and general intercellular information transfer processes involving hormonal and electrical signals.

Defects in the composition, structure and function of the cell membrane are the cause of many serious and widespread diseases in man, including renal tubal failure, certain hemolytic anemias and cancer.

Had the funding Institutes been only interested in projects which produced immediate marketable results, none of this understanding would have been possible.

Had scientists not been curious about the more fundamental questions, we would still view the cell membrane as an inert bag whose only function is to hold the cell together.

It is fortunate that Congress has had the vision to fund Institutes such as NIGMS. In fact, the world leadership of our country in the biomedical areas is, in my opinion, a direct result of the continuity of funding and the maintenance of a sold research infrastructure in areas that hold promise for the future.

Yes, we need applied research, particularly in medicine, but experience has shown us that this is not enough. To make the great leaps forward, we rely critically on knowledge that can only come from basic research.

In the current economic environment, there may be a tendency to view basic scientific research as a luxury, making it an easy target for those who seek quick-fix budgetary solutions. It may also be politically difficult to justify non-categorical programs, such as those supported by NIGMS, if one simply looks at the short-term return for the dollar, or if immediate direct applications are expected.

A more thoughtful look at the projects that NIGMS funds, however, tells a very different story. These research grants and the students trained with Institute funds are the foundation upon which our country's scientific future in biology and medicine is built.

In fact, the NIGMS is unique in this respect. There is no question in my mind that the broad charter of NIGMS and its visionary role has benefited biomedical sciences in two crucial ways:

First, it has promoted research which is on the cutting edge of our scientific disciplines; and second, it has financed the training of the new generation of scientists which will continue to carry this research forward.

Mr. Chairman, I would be remiss if I did not mention the drastic reductions in funding proposed for NIGMS in 1987. The 1987 budget for NIGMS calls for a total number of new and competing grants of 689. This is 283 fewer grants than the 972 level appropriated by Congress in 1986.

Even more distressing is the fact that, although prior obligations will be honored, there are no funds provided for new training grants in 1987.

As a working scientist, I am deeply disturbed by these cuts. Biomedical research has already felt the impact of the Gramm-Rudman-Hollings law in 4.3-percent reductions. In my judgment, should these cuts go unchecked by Congress, we run the risk of seriously jeopardizing our scientific infrastructure.

It is not only research that is at stake, it is the demoralizing effect these cuts have on scientists. As an established investigator, the funding uncertainty limits my ability to plan and to pursue areas which, although promising, may not directly impinge on current projects.

The situation for new investigators is even worse. More and more new investigators are deterred from pursuing careers in academic research due to the pressing economic situation.

This trend is already creating serious problems in the engineering field. New college graduates prefer to devote their efforts to the pursuit of more lucrative industrial careers.

With fewer and fewer students seeking graduate degrees, our universities are finding it harder to maintain adequate supplies of Ph.D.s to train new generations. If the same pattern develops in the biomedical field, the results could be disastrous for medicine.

I would like to request with respect that the funding level in the 1987 NIGMS budget for new and competing research grants be returned to the 1985 level of somewhat less than 1,000. I believe also that it is of critical importance that the number of trainees in the 1987 NIGMS budget be returned to the 1985 level of 3,400.

Mr. Chairman, I wish to thank you again for this opportunity to air my views. I am confident that your leadership will, as it has in the past, preserve and enhance crucial programs such as those at NIGMS.

Mr. STOKES. Thank you, Dr. Thompson, for your appearance here, and the excellent testimony you have given us.

This concludes our hearings for today. The committee will reconvene on Monday at 2 p.m. in the afternoon.

MONDAY, MAY 5, 1986.

CENTERS FOR DISEASE CONTROL

WITNESS

GEORGE K. DEGNON, EXECUTIVE DIRECTOR, ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

Mr. NATCHER. Our first witness this afternoon is Mr. George K. Degnon. Come around, Mr. Degnon, we will be pleased to hear from you.

Mr. DEGNON. Thank you for this coveted opportunity. I ask that my written statement be included in the record, and I will summarize a few points for you.

Prevention is the backbone of public health efforts at the State and local level, and while funding for important biomedical research and for the payment of care through medicare and medicaid have increased by quantums over the last 15 years, funding for prevention and the prevention block grant is at $90,000,000, which is the same level authorized in 1970.

So I am here to urge today that we take full advantage of our capacity to prevent disease and illness, rather than pay the higher cost of sickness care.

The prevention block grant supports a diversity of public health activities. Diversity is needed because we don't know where the next health crisis is going to be: Measles, contaminated food, toxic syndrome, product tampering or even AIDS, so $98,500,000 is recommended for the prevention block grant; and we justify this with a truism that each dollar of this authorization that we save today will spend many times over for tomorrow for sickness and illness care.

In the area of vaccines, nowhere in the data supporting preventive activities more clear-cut than with immunizations, which substantially decrease disease and reduces the net medical costs.

Despite numerous studies of cost-benefit, one by the Office of Technology Assessment of the Congress, State Health Departments are facing a crisis today with childhood immunizations, and the cost of vaccines next year will double, and I have details in my statement.

Many States are now beginning to set targets to immunize fewer children, and we have had the theory all along of herd immunity. If we immunize enough children, we will protect those who are not immunized.

As far as measles, this theory will be challenged in the next few years. I would like to see a request for iron lungs, because we have not adequately funded our polio vaccination to date.

There are so many diseases for which we can do so little, but with immunizations, we have an unambiguous opportunity to prevent disease and save lives. So that we do not have dramatic reductions in the number of children immunized, the committee is urged to appropriate $93,400,000 for the immunization programs at CDC.

The Administration is proposing cutting $5,000,000 in TB control. TB is on the rise. And the Administration has cut $5,000,000 from the Diabetes Control Program. My statement offers justification for the committee to consider the tremendous advantages of these two programs and to reinstate the $5,000,000 for TB and diabetes control.

In the area of sexually-transmitted diseases, they are on the increase, 12,000,000 new cases. $58,000,000 is recommended for grants to States which is desperately needed to get the sexually-transmitted disease programs back on track.

Last year, 25 to 30 percent of that budget was focused away from the traditional sexually-transmitted diseases and spent on AIDS.

That brings me to the next issue. AIDS is no longer focused in just five or six States. There is a shift now, and there are cases in every State throughout the Union.

The only tools we have, testing for antibodies, counseling in education on risk reduction behavior, these are costly activities, Mr. Chairman, because they are manpower-intensive, but they are also necessary activities because with AIDS today, we only see the tip of the iceberg.

The 20,000 cases reported up through last month, that number will double, and this time next year, there will be 40,000 cases. Two or three times as may patients exist with ARC, and there is an estimated 1,000,000 people affected with the virus who are asymptomatic, capable of spreading it to friends and loved ones.

These facts call for dramatic increase in support for AIDS prevention, epidemiology and education. $80,600,000 is recommended at the fiscal year 1987 minimum just for the AIDS activities in the CDC.

In summary, Mr. Chairman, the Federal spending for these preventive programs is an investment in excellence, in Federal, State and public health efforts, in which you and the other members of the Congress serve as proud partners with your colleagues at the State and local level.

I would urge our recommendations which have been summarized in our statement.

[The statement of Mr. Degnon follows:]

STATEMENT

OF

THE ASSOCIATION OF STATE

AND TERRITORIAL HEALTH OFFICIALS

ON

FISCAL YEAR 1987 APPROPRIATIONS

APPROPRIATIONS SUB-COMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES

UNITED STATES HOUSE OF REPRESENTATIVES

MONDAY, MAY 5, 1986

2:00 P.M.

George K. Degnon

Executive Director

Mr. Chairman and Members of the Committee:

My name is George K. Degnon and I am Executive Director of the Association of State and Territorial Health Officials (ASTHO). Thank you for the opportunity to appear before the Subcommittee to present, on behalf of ASTHO and the State Health Departments throughout the nation, some of our recommedations on the FY'87 Appropriations bill. The particular focus of these comments are the programs of the Centers for Disease Control where some of our nation's most cost effective, preventive health programs are located.

The Centers for Disease Control is an outstanding organization dedicated to developing and applying the technology and methodology needed to prevent unnecessary illness and premature death. This task is accomplished through an extremely close relationship between the CDC and State Health Departments. The states work synergistically to insure that the scientific breakthroughs of the National Institutes of Health and the major medical centers around the world are effectively applied for the benefit of the American people. The importance of this task in the scheme of government is clearly a critical one. Our prior accomplishments, and the prospects for improvement in the Nation's health are threatened by the funding cuts proposed for the FY 87 CDC budget. All of us understand the importance of balancing the federal budget, but the mission of the CDC should not be placed at risk in order to achieve budget targets that are, with respect to health, somewhat illogical from the standpoint of the long-range savings to be achieved through prevention. The Association of State and Territorial Health Officials asks you to address this issue and appropriate the recommended increases for these cost effective preventive health programs.

The Preventive Health Services Block Grant is clearly the backbone of public health and it is the only source of federal funds specified for innovative prevention activities available to the states. Programs targeted by the Prevention Block Grant include hypertension reduction, health education, dental health, emergency medical services, and violence prevention. In addition, these funds are utilized to supplement other resources for immunization programs, maternal and child health services, communicable and infectious disease programs, as well as providing states with the capacity to deal with emerging new health concerns such as AIDS, environmental health hazards, and other problems.

States also utilize prevention block grant funds as a principal source for the development of innovative programs in the area of health promotion and disease prevention, risk reduction and health education--and given that approximately 50% of mortality is related to lifestyle--more funding in this area is needed and it will yield great economic and social benefit.

It is especially troublesome that the Administration has chosen to either reduce or straight-line components of the CDC immunization budget. Nowhere are the data supporting prevention activities more clear-cut: Vaccination substantially decreases disease and reduces net medical costs. Your own Office of Technology Assessment concluded that a 1983 comprehensive program using a combined vaccine for measles, mumps and rubella would have saved $378 million in direct treatment costs, which alone would pay for the vaccination program. These cost savings would have also saved 800 lives and prevented 4,000 cases of encephalitis, which is a complication of these diseases. It is fiscally unsound to underfund immunization when the data are so clear that investment in immunization programs significantly benefits our children and their parents.

Today there is a new vaccine available for haemophilus influenzae, an infection that can permanently disable or kill. This vaccine was developed with substantial support from the federal government, yet it is the only childhood vaccine not paid for by federal funds. At $3.00 a dose it is clearly cost-effective. Please imagine the frustrations of physicians and public health officials as they count the number of children affected by this potentially lethal disease, knowing that vials of the vaccine sit unused. Imagine the frustration of those scientists who spent years developing the vaccine, as the fruits of their labor go unused by a significant proportion of the population. It is incredible to me that we are able to mobilize our efforts in many cases to provide a necessary and beneficial $100,000 transplant, yet a $3.00 vaccination seemingly cannot be accommodated. This is wrong, and it is unjust. Haemophilus influenzae meningitis is a known complication of haemophilus influenzae infection, preventable by vaccination. An average hospital stay to take care of a child with this illness could cost up to $3,300, which in many cases will be partially reimbursed by the federal government through the Medicaid program. That $3,300 would purchase 1,100 doses of the vaccine which would keep children well.

Because of liability issues, the costs of many vaccines continue to increase. The CDC has experienced a 98% increase in the cost of oral polio vaccine, a 24% increse for MMR vaccine, and anticipates a 25 - 100% increase for the DPT vaccine. Our estimates are that CDC will need an additional $7 million for polio and MMR vaccine, and an additional $6 million for DPT vaccine in 1987 to maintain state and local vaccine supplies at the 1986 level. In addition, the Administration's proposal has eliminated the vaccine stockpile that safeguards us against epidemics and production short-falls. The Association of State and Territorial Health Officials requests a minimum of $15 million for the vaccine stockpile program and a total of $10 million to assist in program operations at the state and local level.

Members of the committee, there are so many diseases for which we can do so little. Immunization is an unambiguous opportunity to prevent disease and to save lives. Your continued interest and action to adequately support these programs is urgently needed this year for fear that without increased federal support we will begin to see dramatic reductions in the number of children immunized in public programs.

The Administration has decided that tuberculosis and diabetes control programs are no longer necessary at the federal level, for both have been eliminated from the CDC FY 87 budget request. The rate of tuberculosis increased last year. A disease which should be eradicated (and many think it is because we have seen the close of tuberculosis hospitals in our lifetime) is now becoming more widespread. State health departments throughout the nation are concerned, as in Indiana where the local health department discovered a kindergarten teacher with a full blown case of tuberculosis. That health department's staff, in a short period of time, identified by name and location a total of 601 contacts of the kindergarten teacher, including 54 kindergarten students, 44 1st graders, 262 2nd - 5th graders, and 151 out-of-state school children. As a result of that investigation, 56 of the above mentioned contacts required preventive tuberculosis treatment and 2 cases of the disease were identified that were attributed to the contact. If caught in time, tuberculosis can be treated. If not caught in time, tuberculosis can kill. The American Lung Association documents a 2% increase in the number of tuberculosis cases identified last year in the United States. A study done in Connecticut showed that the State Health

Department saved $81,000 last year in hospitalization costs from the money invested in tuberculosis control. A similar effort in Massachusetts saved the Commonwealth $250,000. We enthusiastically recommend that $5 million be restored to the tuberculosis control program.

Approximately ten million people in the United States suffer from diabetes, but only half of those people know it. The devastating compications that can result from untreated diabetes mellitus include blindness, heart attacks, amputations and kidney failure which may require chronic dialysis and/or kidney transplantation. This country spends billions of dollars through Medicare, Medicaid, and privately purchased health insurance, to treat these complications. Here again we urge that the Committee to reinstate the $5 million to the Diabetes Control Program so that our public health programs can spare our citizens the human misery and the unnecessary costs of care. One activity of the program provides ophthalmology screening for patients who might otherwise not have access to medical care, thereby obviating possible blindness by timely medical intervention. NIH estimates that 2/3 of all diabetes retinopathy cases could be prevented. Data from successful programs in Utah, Mississippi and California have clearly demonstrated that risk-factor reduction, decreased incidence of blindness and decreased risks of major birth defects have resulted from programs that are being adequately funded.

Nowhere is the work of the CDC better seen than in the area of sexually transmitted diseases. Greater attention must be focused on preventing sexually transmitted diseases which claim 12 million new cases annually. We have the public health skills to attack this area but simply lack the resources to effectively deal with and prevent the problem. Chlamydia has been identified as more prevalent than gonorrhea in our population. Chlamydia affects 3-4 million people every year, and contributes substantially to the incidence of infertility, ectopic pregnancy and miscarriage in our society. The CDC has promulgated guidelines for a national program, but federal funds have not been dedicated to this program that would save a substantial portion of Medicaid funds now spent to treat the effects of chlamydia infections. We need, today, a comparable federal investment in chlamydia prevention and early treatment, as was done for gonorrhea in the early 1970's. In spite of this need, the Administration's budget for sexually transmitted diseases has been straight-lined for 1987. The Committee is urged to reject the status quo and demostrate its commitment to more aggressively attacking Sexually Transmitted Disease by appropriating a minimum of $58 million.

The final category of expenditures I wish to address is that for the Acquired Immune Deficiency Syndrome - AIDS. Although the Congress has been generous with respect to its appropriations for AIDS, the Administration's FY87 request is not sufficient to meet the need to control the Nation's number one public health problem. Although it is quite appropriate to invest in the search for effective treatments and for a vaccine, the only weapon currently available is education for prevention. Virtually all of that effort stems from programs at the state and local level. It is crucial that the Congress restore funding for alternative test sites and that the Congress substantially increase funding for prevention, health education and risk reduction. In San Francisco and in New York, approximately 75% of the high risk population has already been infected with the virus. and for them, medical science and public health have little to offer, for once infection occurs, the virus replicates and is spread to others through sexual contact and blood to blood contact as it slowly kills its host. In most states far fewer of the high risk population has been exposed to the virus. Thus, in these states we have an opportunity to keep from becoming a San Francisco or a New York with respect to this desease. That opportunity will surely be lost if we are unable to sustain the vigorous education and prevention efforts we have started. It is unlikely that a vaccine or a treatment will be available prior to the early 1990's but approximately 2 million people in the United States now harbor the virus and are capable of spreading it to others. We urge you to make certain that our prevention and risk reduction efforts are sufficiently funded. ASTHO recommends that the minimum appropriation for AIDS activity at CDC (surveillance, epidemiology, laboratory, prevention and risk reduction, demonstration programs, alternative test sites, health education including the hot line) be 80.6 million.

Finally, during the past 2½ years ASTHO has been preparing a newsletter on state preventive health activities entitled Prevention Notes which is shared with each member of this Committee. This communication addresses major public health activities and reports on the many innovative and good, basic public health efforts of state agencies. Listed below are topics covered in previous issues and further information is available from our office on these or other state programs. Once again, special thanks are expressed to each member of this committee for your continued good interest and support of our nation's public health efforts.

- Health Risk Assessment
- Health Education-Risk Reduction
- Hypertension
- Protection of Public Water Supplies
- Emergency Medical Services
- Rape Prevention
- Smoking

- Infectious Disease
- Tuberculosis
- Injuries
- Lifestyle: Diet and Exercise
- Challenges for Immunization Programs in the United States
- Public Health Nutrition Services
- Public Health Laboratory Services
- Cancer Prevention and Control
- Public Health Nursing
- Innovative Programs
- State Health Statistics Agencies
- Health Facility Licensure & Certification
- Hazardous Waste Sites and the Protection of Public Health
- Home Health Care
- 1990 Prevention Objectives
- Occupational Health

SUMMARY OF ASTHO RECOMMENDATIONS

SELECTED CATEGORIES
CENTERS FOR DISEASE CONTROL BUDGET

	FY 1986 Appropriation (Thousands)	FY 1987 Request (Thousands)	FY 1987 ASTHO Recommendations (Thousands)
Preventive Health Block Grant	90,958	89,000	98,500
Sexually Transmitted Diseases:			
Grants	46,511	45,510	58,000
Program Operations	9,774	9,943	9,943
Immunization:			
Grants	47,359	47,666	68,400
Program Operations	8,235	8,346	10,000
Vaccine Stockpile	4,000	0	15,000
Tuberculosis Grants	5,000	0	5,000
Diabetes Control	5,000	0	5,000
AIDS (CDC)	64,925	45,409	80,600

MONDAY, MAY 5, 1986.

AIDS PROGRAMS

WITNESS

DR. DAVID JENNESS, CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Mr. NATCHER. Our next witness is Dr. David Jenness. Come around, Doctor. Doctor, we are glad to have you back before the committee, and we will be pleased to hear from you.

Mr. JENNESS. Thank you very much, Mr. Chairman.

I was a constituent of his for the first half of my life, and sometimes I wish I were still there. My scientific training is in biobehavioral psychology and neuroscience, but this afternoon I am speaking as Executive Director of the Consortium of Social Science Association, COSSA, which represents American scientists from the social and behavioral science disciplines, serving as a bridge between the academic research community and the Washington community.

I am not here to tell this committee about the seriousness we face with AIDS. I want to focus on what we can do about it.

It is difficult to exaggerate the vastness and complexity of the problems with which our entire society must struggle in the face of AIDS. Federal support for biomedical research has, of course, been of paramount importance.

But the Federal record of support for non-biomedical research critical to the resolution of the AIDS crisis is not even comparable.

Most experts agree that until biomedical research achieves ways to prevent or contain AIDS, the most powerful weapon to stem the tide of the epidemic will be found in focused public education and persuasion.

Passive education, just putting the facts before the public, will not work. This is especially true when "the facts" are stated vaguely and euphemistically, for reasons we all understand.

Even when facts are put forward in a clear, powerful way, individuals do not always pay attention, or follow what they know. Research psychologists have demonstrated that individuals do not calculate risk accurately, especially when there is a long delay between the behavior and its possible outcome.

Sociologists have shown that public education succeeds best if the message is conveyed via trusted intermediaries, rather than by impersonal means alone.

And as anthropologists know, public messages do not get through to specific cultural groups when they are conveyed in inappropriate forms.

On the other hand, the conveying of pertinent information through personal networks may be greatly enhanced by broadscale public efforts. Social and behavioral scientists have had significant successes in designing such campaigns.

In the Stanford Three-Community Study, for example, conducted in the late 1970s, knowledge of factors conducive to cardiovascular disease was increased, and actual risk behaviors were decreased, by public education campaigns and face-to-face counseling in three different communities.

The combination of mass media messages and intensive intervention at the personal level was more effective than media campaigns alone.

Unfortunately, there are some groups where we know that even focused information campaigns are relatively unsuccessful. How do we reach deteriorated drug addicts who have been dealt out of society, and who may by personality be risk-seeking? Or prison inmates who have little to lose?

On balance, however, experience to date has been hopeful. With regard to AIDS specifically, the gay community has shown a remarkable responsiveness to the message. Venereal disease rates in cities with high incidences of AIDS have dropped dramatically. This drop is the envy of public health authorities and biomedical experts who have found it so difficult to persuade people to stop smoking or drinking, or to buckle up while driving.

However, it is a fallacy to believe that all those who engage in homosexual behaviors that put themselves and others at risk relate to "the gay community," or listen to gay community leaders. There are many people who have no such identification, and no exposure to those sources of influence. We must design means to reach them.

With regard to young people using drugs, we must urgently investigate what blend of peer pressure and public information will work, to persuade them that injecting drugs is even more likely than ever to be suicidal.

A similar, tailor-made program must be undertaken for women of child-bearing age.

A different kind of group that must be reached includes public leaders and officials who are called on to make crucial, agonizing decisions for the public good: School boards, employers, public health officials, police and the courts, those who run social services, perform counseling, or determine insurance guidelines and practices.

Here especially, the authority of the Department of Health and Human Services or the Centers for Disease Control is essential.

Part of the Federal Government's information responsibility is to give local authorities and leaders means for resisting unhelpful local pressures. We must realistically face the fact that fear and ignorance in the general public breed counterproductive attitudes and we must help those with responsible positions to understand those attitudes.

We must help those with responsible positions to understand and meet those attitudes. The participation of sociologists and political scientists who study the relationship between the community and its leaders will be essential in this effort.

Mr. Chairman, the portion of the Federal funding for the battle against AIDS that is currently earmarked for public education and related purposes is grotesquely inadequate. Public information cannot be left to the mass media, on the one hand; to gay community groups, on the other. Government must lead; what we don't know will kill some of us.

There is historic precedent for such a campaign, in the history of invention and intervention in epidemics, in widespread malnutrition, in sanitation, in ridding the environment of dangerous toxins and infectious agents.

Systems of quarantine, of locating the carriers of disease, of persuading people to undergo vaccination or seek treatment, have worked in the past.

Organizations that give support need support, from the political system as well as from the local community. Do we know how to encourage and sustain such groups, not just in the gay community but, for example, on the university campus or in the working force?

Consider also the important field of health economics. The projected costs of caring for the cases of AIDS now known and of those presently infected who, barring a medical miracle, will fall ill, is absolutely staggering.

Health economists must estimate such costs. Economists, medical sociologists, and others must study how care can be delivered, and at what expense, to those showing signs of AIDS-related illness, for it is possible that, with an efficient system, some of those lives may be saved.

Social scientists in general must study the costs of AIDS to particular social systems and sectors; for example, public education, the work place, the already stressed welfare systems.

Experimentation with providing AIDS patients with most of their care outside hospitals, in San Francisco, has provided care of equal effectiveness, at about one-fourth the average cost of hospital-centered treatment.

What do we need to know about the San Francisco experience? What are the impediments to effectively modifying policies to allow these economies and efficiencies to be adopted more widely?

Mr. Chairman, I do not know what the proper funding level for the campaign against AIDS should be. I do know that Federal action, coordination, leadership, research, demonstration, service provision, must be intensified; money is only part of it.

A strong and visible public intervention campaign must be mounted, based on what is already known through research in the behavioral, social and communication sciences.

Beyond this, and here also this committee's influence could be important in a program of integrated multidisciplinary long-range research. There must be an integration of effort from the social and behavioral sciences and all parts of medicine, not just the laboratory and the clinic, but those working in the field and in the community.

The various NIH and other PHS agencies, or some central office should be encouraged to organize, stimulate and fund a wide range of social science research, demonstration and evaluation.

While I believe the emergency and the present danger is very great, I also believe the scientific and human capacity is there to be tapped, and that the effort will succeed.

I would be pleased to amplify any of my comments or answer any questions.

[The statement of Mr. Jenness follows:]

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TESTIMONY OF DAVID JENNESS, PH.D.

Consortium of Social Science Associations
(COSSA)

on the

FY 1987 APPROPRIATION FOR
RESEARCH ON AIDS

Prepared for the
SUBCOMMITTEE ON LABOR, HHS, EDUCATION AND RELATED AGENCIES

HOUSE APPROPRIATIONS COMMITTEE

The Honorable William Natcher, Chairman

May 5, 1986

American Anthropological Association • American Economic Association • American Historical Association • American Political Science Association
American Psychological Association • American Sociological Association • American Statistical Association
Association of American Geographers • Association of American Law Schools • Linguistic Society of America

Good afternoon. My name is David Jenness. My scientific training is in biobehavioral psychology and neuroscience. Most of my research was done at the Columbia University Medical School. I have also served on the staff of the Social Science Research Council in New York. This afternoon I am speaking as Executive Director of the Consortium of Social Science Associations (COSSA). COSSA represents more than 185,000 American scientists across the full range of the social and behavioral science disciplines, serving as a bridge between the academic research community and the Washington community. [A list of COSSA Members and Affiliates is attached.]

I am not here to tell this already well-informed committee about the seriousness of the medical and societal crisis we face with regard to AIDS. I want to focus instead on what we can do about it. However, I want to make two preliminary comments on the nature of the problem. First, the extent of the problem. Both scientifically and practically, the picture is unclear, but the news is not encouraging. The basic statistics of the disease are not very reliable. Estimates of the number of Americans thus far infected by the AIDS virus range between 700,000 and 1,400,000. If as few as 10% of those persons manifest clinical disease, a conservative assumption, deaths will amount to 70,000 to 140,000 cases, hospital costs to $10 to $20 billion, and associated economic losses to $30 to $60 billion.

However, the length of time between infection and illness, in cases where that occurs, can be longer than had been thought -- which makes it more difficult to predict how many cases of illness there will be, and when they will appear. And the estimate of the proportion of those exposed to infection who eventually will fall ill is also being revised upward, which means that -- considering only those now exposed -- we may have a larger problem on our hand than we thought six months or a year ago. These grim facts represent the human and economic costs exacted by the present distribution of the AIDS virus. Of the epidemic continues, as is certain without an effective public health control program, and if, as is possible, it becomes established in the heterosexual population, then the toll will be far greater.

Meanwhile, the likelihood and timing of the development of a cure or a preventive vaccine remain unknown.

Second, a comment on the definition of those for who AIDS is a danger. The concept of special 'at risk' groups is very unsatisfactory. It is both too broad and too narrow. The major routes of transmission of the virus appear to be known — at least in this society at this moment. Given that knowledge, it is crucial to learn more about those routes and mechanisms, and to set about altering circumstances and behaviors to intercept them, so that the transmission of the disease is diminished or stopped. It simply breeds confusion to say that male homosexuals or drug users are 'at risk,' when more precise knowledge is available. Teenagers are not meaningfully 'at risk' for unwanted pregnancy — except when they practice, or fail to practice, particular behaviors. Middle-aged males are not especially 'at risk' for lung cancer — except when they smoke. The concept of large, undifferentiated 'at risk' groups is misleading, because it is too broad.

At the same time it is too narrow, because it gives a false sense of security. Heterosexual couples who practice the same sexual behaviors that some homosexuals do, are vulnerable. Teenagers indulging in sexual experimentation under certain conditions are vulnerable. Accidentally infected women may — it is not entirely clear — be carriers of the disease and may unwittingly infect men and infants. Those who depend on donated blood for any number of reasons are at some risk, though this has been very substantially diminished. The diabolical nature of AIDS is that there are countless ways in which individuals who do not belong to the so-called risks groups may in fact become infected and may unwittingly infect others, over a very long period of time.

It is difficult to exaggerate the vastness and complexity of the problems with which our society must struggle in the face of AIDS. On the biomedical front the successes have been extraordinary. Federal support for the biomedical research has, of course, been of paramount importance. Unfortunately, the federal record of support for non-biomedical research critical to the resolution of the AIDS crisis is persuasion, and exhortation — what blend of peer pressure and public information — will work, to persuade them that injecting drugs is even more likely than ever to be suicidal. A similar, tailormade program must be undertaken for women of child-bearing age.

A different kind of group that must be reached in an effective, focussed way includes public leaders and officials who are called on to make crucial, sometimes agonizing, decisions for the public good: school boards, employers, public health officials, police and the courts, those who run social services, perform counselling, or determine insurance guidelines and practices. Here especially, the authority of the Department of Health and Human Services or the Centers for Disease Control is essential, to convey what is and is not known to those who must make such decisions. Local authorities vary widely in their degree of experience with the problem and with the scientific and public policy issues involved. They are also at the mercy of those in the general public who are woefully misinformed or who have special axes to grind. Hence, part of the federal government's information responsibility is to give local authorities and leaders means for resisting unhelpful pressures. We must realistically face the fact that fear and ignorance in the general public breed counter-productive attitudes, and we must help those with responsible positions to understand and meet those attitudes. The participation of sociologists and political scientists who study the relationship between the community and its leaders will be essential in this effort.

Policy makers and community leaders at all levels of government need accurate information and critical analysis of alternative political, economic and social responses to the AIDS epidemic. Is mandatory reporting effective or, as many believe, counter-productive because it will lead persons who fear being stigmatized to stay away from health services? What steps are needed to protect the victims of the disease from discrimination at the workplace, in the schools and in housing? What is the cost-benefit ratio of mandatory prenatal testing? Screening, when it is employed at a low risk population, yields many more false positives than true not even remotely comparable. Parallel research, much of it by social and behavioral scientists, needs to mobilized to much a greater extent to help us resolve the immense social, psychological, and economic problems which accompany the medical reality of the disease.

Most experts agree that until biomedical research achieves means to prevent or effectively contain AIDS, the most powerful weapon to stem the tide of the epidemic will be found in focussed public education and persuasion. Passive education — just putting the facts before the public — will not work. This is especially true when 'the facts,' are stated vaguely and euphemistically — for reasons we all understand. If intravenous injection using shared needles is what is dangerous, that has to be said, as distasteful as that may be. If specific sexual practices are dangerous, it is crucial to convey clearly what they are. The coy phrase "exchange of bodily fluids" has created needless fear about the transmission of the disease by saliva, tears, or sweat.

Even when facts are put forward in a clear, powerful way, individuals do not always pay attention, or follow what they know. Research psychologists have demonstrated that individuals do not calculate risk accurately, especially when there is a long delay between the behavior and its possible outcome. Sociologists have shown that public education succeeds best if the message is conveyed via trusted intermediaries, rather than by impersonal means alone. And as anthropologists know, public messages do not get through to specific cultural groups when they are conveyed in inappropriate forms or situations. On the other hand, the conveying of pertinent information through close personal networks or associations may be greatly enhanced by broadscale public efforts. Social and behavioral scientists have had significant successes in designing such campaigns. In the Stanford Three-Community Study, conducted in the 1970s', knowledge of factors conducive to cardiovascular disease was increased, and actual risk behaviors were decreased, by public education campaigns and face-to-face counselling in actual medium-sized communities. The combination of mass media messages and intensive intervention at the personal level was more effective than media campaigns alone, though there is evidence that mass media efforts are crucial in maintaining healthy behavior in the target community. Interestingly, spouses of those who received individual attention also changed their knowledge of risk factors, suggesting that close networks do influence those who are not the direct objects of systematic efforts. Similar results have been shown in communities of Northern Finland, where public education and more behaviorally oriented efforts have resulted in the reduction of dangerous fats from the typical diet.

Unfortunately, there are some groups where we know that even focussed information campaigns are relatively unsuccessful. How do we reach deteriorated, stigmatized drug addicts who have been dealt out, or have dealt themselves out, of society, and who may by personality be risk-seeking to begin with? Or prison inmates who have little to lose? These are difficult challenges, which social and behavioral scientists can begin to answer.

On balance, however, experience to date has been hopeful. With regard to AIDS specifically, the gay community has shown a remarkable responsiveness to the message. In large cities, at least, sexual behavior is changing. Venereal disease rates in cities with high incidence of AIDS have dropped dramatically. This drop is the envy of public health authorities and biomedical experts who have found it so difficult to persuade people to stop smoking or drinking, or to buckle up while driving. There is also some evidence that sexually active young heterosexuals are also changing their behaviors in response to a perceived threat. In other words, a clear-cut message about imminent and dreadful illness does get across.

However, it is a fallacy to believe that all those who engage in homosexual behaviors that put themselves and others at risk relate to 'the gay community,' read the gay press, or listen to gay community leaders. There are many people who have no such identification, and no exposure to those sources of influence. Once again, we must design means to reach them. Again, the message must be, not that homosexuals are at risk but that specific acts and practices are risky. With regard to young people using drugs, we must urgently investigate what combination of influence, positives. Are we prepared to back up screening by making therapeutic abortions available? If not, screening will be costly in both human and economic terms but will produce no benefit.

Mr. Chairman, the portion of the federal funding for the battle against AIDS that is currently earmarked for public education and related purposes is grotesquely inadequate. Public information cannot be left to the mass media, on the one hand; to gay community groups, on the other. Government must lead: what we don't know will kill some of us.

There is still another level of effort that must be undertaken. I began by observing that we are faced with a major societal crisis, the dimensions of which are still unknown. A major commitment to research in the social and behavioral sciences — working with but extending beyond the biomedical and public health arena — is urgently needed. Such efforts must include an emphasis on what I will call social invention — that is, new responses by individuals, groups, communities to unforeseen problems and opportunities.

There is historic precedent for such a campaign, in history of invention and intervention in epidemics, in widespread malnutrition, in sanitation, in ridding the environmental of dangerous toxins and infectious agents. Systems of quarantine, of locating the carriers of disease, of persuading people to undergo vaccination or seek courses of treatment, have worked in the past. With regard to AIDS, as noted previously there is evidence that members of the gay community are taking steps to control the spread of the disease. Money is being raised. Home and hospice care is being provided. Those who are already infected are being induced to act altrustically, to spare others. Gay community leaders are bringing the real facts of the crisis to the authorities, rather than the other way around, and are instructing the hospital administrators, the police and the courts, city councils, etc., in the realities of what kinds of social control and persuasion will and will not work. The study of voluntarism in this society is a well-established research tradition. We must build on this tradition in discovering how informal groups and organizations form, thrive, meet challenges, succeed, and disappear. What response from the larger community will ensure the viability of such associations as service-performing institutions? Organizations that give support need support, from the political system as well as from the local community. Do we know how to encourage and sustain such groups, not just in the gay community but, for example, on the university campus or in the working force? Political scientists, sociologists, and other scholars must study the politics of AIDS. We must know how delicate balances between civil liberties and public duty shift as circumstances alter, and how particular groups act in concert with or against others.

Consider also the important field of health economics. It has been estimated that one case of AIDS costs as much as a single heart transplant. The projected costs of caring for the cases of AIDS now known and of those presently infected who, barring a medical miracle, will fall ill, is staggering. The eventual over-all cost to our society may be incalculable. But health economists and others must estimate such costs, or our health care system may collapse under the burden. Economists, medical sociologists, and others must study how care can be delivered, and at what expense, to those showing signs of AIDS-related illness, for it is possible that, with an efficient system, some of those lives may be saved. Social scientists in general must study the costs of AIDS to particular social systems and sectors: for example, public education, colleges and universities, the workplace, the already stressed welfare systems. The costs of home care must be compared against the costs of hospital care. Experimentation with providing AIDS patients with most of their care outside hospitals, in San Francisco, has provided care of reportedly equal effectiveness, at about one-fourth the average cost of hospital-centered treatment. What do we need to know about the San Francisco health delivery experience? What are the impediments to effectively modifying policies to allow these economies and efficiencies to be adopted more widely?

The separate issue of insurance, insurability, and indemnification in society must be studied, and alternative choices laid out. What groups will denied basic medical insurance protection? Who will pay their medical costs? How many individuals will have claims denied? What are reasonable screening procedures for potential insurance coverage? To what degree will persons be individually liable through lawsuits and other claims for their personal behavior, witting or unwitting? Will spouse sue spouse, or spouse's estate?

How can we best assure that a vaccine, once it is developed in the laboratory, becomes available for public use when pharmaceutical companies are withdrawing from the field becasue of the liability risk? Indeed, the very field testing of an AIDS vaccine in humans raises major social and ethical questions. On whom should it be tested? Presumably, the answer would be seronegative persons in high risk groups. But if they practice "safe sex" they will be exposing themselves to the unknown risks associated with a new biologic product for an uncertain protection they may not need. What are the ethics of using a placebo control group in so fatal a disease, since those vaccinated may believe themselves to be safe and thus take risks? How long must we wait before we know the vaccine is effective as well as safe, in view of the long latency period between infection with AIDS virus and the appearance of clinical disease? The issues need to be addressed now; they require the expertise of social scientists in designing field trails.

Equally important, though very different in nature, is research on the emotional, cognitive, and social aspects of how individuals take responsibility for their own actions. Some people who are at risk or even ill take charge of their own fates and show responsibility for others, with extraordinary effectiveness. Others fall apart, and become social menaces. The close study of interpersonal influences and family dynamics is obviously crucial as regards the avoidance of exposure, or support and caring for the ill. To what extent will parents control their children's behavior — or children defy their parents? It is also essential to study aspects of behavior that affect proneness to illness on the physiological level. AIDS is a disease that attacks the immune system, and there is a whole chain of factors — diet, exercise, avoidance of other infection, life style, patterns of contact with others, social support networks -- that play a part in determining who does or does not become at risk, and who does or does not fall ill. This is the province of behavioral and health psychologists, sociologists and anthropologists, human geographers, social epidemiologists, and a wide range of other experts.

Cognitive psychologists know a great deal about how individuals conceptualize risk. Social psychologists and sociologists understand risk-seeking behavior in particular types of individuals and in special groups. Sociologists of deviance and urban anthropologists understand some of the dynamics and patterns of addiction, resistance to influence, alienation, etc. Social scientists who study subcultural differences among us certainly must be involved in our efforts at public education and social influence. We cannot reach the minority teenager, the social isolate, the persons who read and speak other languages, affluent teenagers who think it can't happen to them, without the full knowledge that social scientists have gained from research. Not only do we have a responsibility to reach all groups, all ages, all special kinds of people -- but it is simple prudence. As public health workers know, so long as any group remains out of earshot or unaware, we are all in danger.

These are not exotic agenda items for the future. They all need to be addressed beginning now. We are still, in this relatively favored society of ours, coping with societal problems dating from the polio epidemics of the mid-decades of this century, or the great flu epidemic from the First World War. How a society deals with a massive threat to its integrity and wellbeing; how it handles costly and frightening emergencies; how it encourages social invention; how it treats the differentially affected; how it reacts to the death of a large number of its members, and to fear and suspicion among many others — all of these topics need to be studied, and urgently.

Mr. Chairman, I am not competent to suggest what the proper funding level for the campaign against AIDS should be. I do know that federal action — coordination, leadership, research, demonstration, service provision — must be intensified; money is only part of it. A strong and visible public education campaign must be mounted immediately. It must take advantage of all existing avenues and mechanisms: governmental and intergovernmental agencies, existing social structures and groups, and established or newly created voluntary associations. The campaign must be based on what is already known through research in the behavioral, social, and communication sciences.

Beyond this, a program of integrated multidisciplinary longrange research must be designed. There must be an integration of effort from the social and behavioral sciences and all parts of medicine, not just the laboratory and the clinic but those working in the field and in the community. The November 1985 initiative by the Alcohol, Drug Abuse, and Mental Health Institutes is an excellent start, as is the ADAMHA call earlier this month for proposals to set up two or three multidisciplinary research Centers. Now this beginning in behavioral and social research must be reinforced by the contributions of scientists studying other aspects, at all different levels of society, from the individual to the society as a whole. Various of the NIH and other PHS agencies, or, -- if the Congress and HHS leadership so decide — some central office, must be encouraged to organize, stimulate, and fund a wide range of social science research, demonstration, and evaluation. While I believe the emergency and the present danger is very great, I also believe the scientific and human capacity is there to be tapped, and that the effort will succeed.

I would be pleased to amplify any of my comments or answer any questions.

CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

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American Anthropological Association
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Regional Science Association
Rural Sociological Society
Social Science History Association
Society for American Archaeology
Society for the History of Technology
Society for Research in Child Development
Society for the Scientific Study of Religion
Southern Sociological Society
Southwestern Social Science Association
Speech Communication Association
The Institute of Management Sciences

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State University of New York at Stony Brook
University of Tennessee, Knoxville
Texas A & M University
Tulane University
University of Washington
University of Wisconsin, Madison
University of Wisconsin, Milwaukee
Yale University

Mr. NATCHER. Dr. Jenness, you have made an excellent statement. We appreciate your appearance before the committee.

As you know, the amount that we agreed on for fiscal year 1986 was $234,352,000. The sequester of March 1 brought that down to $224,275,000.

Of that amount, we had $15,312,000 for demonstration projects. The Administration hasn't ask for any money demonstration projects in the 1987 budget. The amount before us is $203,482,000, and Dr. Jenness, Mr. Conte and I and all the other members of this subcommittee intend to bring out a good bill, bring out a bill that is commensurate with the problem that we have before us, and I say that to you frankly.

Mr. CONTE. Mr. Chairman, I included an amendment in the bill last year to do the very thing you are talking about: to have an AIDS coordinator. We are watching the development of that very, very closely, because money I don't think is the problem anymore. A few years ago, funding was $28,000,000. Now it is over $230,000,000. Given that, I felt it was very, very important we have somebody on top to be able to coordinate all the agencies in the public health field working on AIDS.

Mr. JENNESS. The figures are not always easy to read, but about 1 percent of the entire AIDS budget is now earmarked for public education and demonstration, and I believe that is too little.

Mr. CONTE. I agree with you.

Mr. NATCHER. Thank you very much, Doctor.

MONDAY, MAY 5, 1986.

AIDS PROGRAMS

WITNESS

GARY B. MacDONALD, AIDS ACTION COUNCIL

Mr. NATCHER. Our next witness is Mr. Gary MacDonald, and we will be pleased to hear from you.

Mr. MACDONALD. It is a real pleasure to hear my colleagues who preceded me talk so eloquently about the need regarding AIDS. Sometimes it feels as if you are crying in the wilderness, but not any longer, and that is a real gratification.

The 120 organizations that we represent would like to commend you and the distinguished members of the subcommittee for your steadfast commitment over the years to Federal AIDS-related funding.

You recognized and acted to resolve this urgent crisis long before the public or private sectors, or Americans in general, understood the necessity for action. I particularly commend you for voting to double AIDS-related funding from 1985 to 1986, and for refusing just two weeks ago to permit the Administration to slash funding for AIDS research and education at this crucial time.

When the history of this epidemic is written, and let us pray that will be soon, you will be remembered as far-sighted legislators serving America's health interests in the best tradition of compassionate public service.

Your commitment has helped bring the Federal Government, the scientific establishment and this society a long way in the past 12 months toward understanding AIDS.

Errors of omission and commission have been made by all of us in the process, but the Council is not concerned now with mistakes of the past. Today, we will focus on the challenges of the future.

Despite the progress that has been made on scientific, medical, educational and social fronts, Mr. Chairman, our society does not yet fully comprehend that AIDS is a long-term reality in this country which requires long-term commitments of funding and determination from all of us.

AIDS is now one of the leading killers of young men in America, and even if a vaccine were available tomorrow, those young men would continue to die in increasing numbers because of infections contracted previously.

More than a million men, women and children are asymptomatically infected with the virus that is believed to cause AIDS. Perhaps as many as 500,000 of them will eventually develop some presentation of illness in the spectrum of HTLV-III infection, and require the complex matrix of services that, for far fewer people now, is already taxing the health care delivery system.

A year ago, when I testified before you, 10,000 cases of AIDS had been reported. Today, that number is almost 20,000. Next year at this time, it will be 40,000 and rising.

Clearly, to act responsibly today in the interests of the future requires that we sit down—legislator, bureaucrat and citizen alike—and develop a comprehensive plan.

Even as we speak, however, no such plan exists. Its absence creates a policy vacuum in which decisions about AIDS that have serious medical, legal and social consequences are being made piecemeal at all levels of Federal, State and local government.

The Council urges you, Mr. Chairman, to put teeth into a reiteration of your past request that the Public Health Service develop a comprehensive and detailed Federal plan of attack on AIDS. It is not enough merely to state goals; the Public Health Service must also tell us how those goals are to be achieved.

Part of the problem is lack of permanent personnel to direct the planning. An Assistant Secretary for Health must be nominated immediately, and a Public Health Service Coordinator for AIDS named.

Once appointed, these individuals must move quickly to strengthen and consolidated the good work already being done. They must also carefully analyze short-term priorities in the context of long-term needs.

Addressing the long-term will require not only a great deal of money over an extended period of time, Mr. Chairman, but also, more importantly, the consistently wise use of those scarce resources.

The Council urges you, Mr. Chairman, to reject what we believe to be the unwise proposal by the Administration to concentrate all fiscal year 1987 AIDS-related appropriations in the Office of the Assistant Secretary for Health.

Lacking permanent staff, a detailed plan of action and a commitment from the Secretary himself for staff and resources to implement it, this proposal could not work even in theory.

Practically, it would deprive Congress of its right to designate specific appropriations for specific purposes. It would also increase the ease with which the Administration could sequester funds and delay progress, as has already happened this year, in order to satisfy political rather than scientific priorities.

In regard to fiscal year 1987 AIDS appropriations, the Council strongly urges you, Mr. Chairman, to consider carefully this documentation from Public Health Service agencies that suggests the need for at least $400,000,000 in overall AIDS funding next year.

The following are priority concerns:

The science of AIDS. Between $60,000,000 and $80,000,000 in funding beyond the current base level is required by the National Institutes of Health to expedite significant recent progress in vaccine research, clinical trials of anti-viral and immune-stimulating drugs, studies involving genetic modeling and protein synthesis and the development of diagnostic devices.

Scientists are on the verge of breakthroughs in all of these areas. An anti-AIDS vaccine, for example, is much closer to realization today than it was even six months ago. To deny scientists the flexibility of funding, and particularly the personnel, the need right now to bring these projects quickly to fruition would be truly "penny-wise and pound-foolish."

Significant additional funding is also required to study the full spectrum of disease caused by the HTLV-III virus. Disturbing new discoveries about the neurological impact of infection must be investigated.

Research now confirms that many more people will suffer from AIDS-Related Complex, neurological and other complications of infection than from AIDS itself. We must learn quickly how this infection behaves in all of its presentations, as well as how those presentations are linked and may be treated effectively so that full-blown AIDS remains what it is today: A rarity.

The psychosocial science of AIDS. In addition to studies of the disease itself, increases of between $10,000,000 and $20,000,000 beyond current base levels of funding are required to study the profound and so far largely negative impact AIDS and HTLV-III infection have had upon our society.

The unquestionably grim reality of AIDS has driven much of the population not toward unity and empathy, but rather toward recrimination, fear and denial. While these extreme reactions may be understandable, they also enhance the suffering and stigma associated with this disease and may actually encourage the spread of a virus whose transmission thrives on ignorance.

Scientists urgently need to example the psychological implications of HTLV-III infection that may or may not progress to presentations of illness; the implications not only for the infected individual, but also for his or her surrounding community.

A principal concern must be how this society will cope wisely and humanely with hundreds of thousands of infected but asymptomatic citizens. Effective modes of counseling and social support must be developed and implemented.

The social and psychological impact of a sexually-transmitted disease that primarily affects citizens perceived to be "outside the mainstream" must also be studied.

Without such firm scientific underpinnings, we risk the institutionalization of fear by default, a fear that has already begun to erode the compassion and good sense that have traditionally made America exemplary among nations.

Health care aspects of AIDS. Four health care demonstration projects about to get underway in cities where incidence of infection is very high must be augmented in 1987 with between $30,000,000 and $50,000,000 additional funding to mount similar projects in areas of the country where infection is not so widespread.

This is money particularly wisely spent, since every dollar devoted now to development of cost-effective and compassionate care will save literally millions later.

Again, attention to the long-term demands that we study the needs and capabilities of States and cities which are not now equipped to handle even one case of AIDS, let alone hundreds.

AIDS education and prevention. Finally, and perhaps most important, is the need for far larger appropriations for AIDS education and prevention activities. These are our only line of defense, both now and for years to come, against the spread of HTLV-III infection. To slight education now, or to conduct prevention programs with inadequate resources, is to guarantee that AIDS will be with us for a generation.

The Council believes the current appropriation for AIDS education and prevention must be increased in 1987 by a minimum of $30,000,000. That would bring it to around $50,000,000.

This level of additional funding is vital to ensure that all 50 States, not just 25 or 30, are capable of educating their at-risk and no-risk populations alike.

Because disturbing instances of AIDS-related ignorance continue to characterize physicians, health care workers, educators and public officials throughout the country, these professional groups must also get immediate enhanced support.

Particular "windows of opportunity" for transmission of the HTLV-III virus, and simultaneously for stopping its transmission, are now clearly evident in minority communities and among adolescents and IV drug users.

For various reasons, these populations are at very high risk of infection because they so far lack the skills to prevent it. Increased funding would focus attention on programs to give them those skills.

While the gay community has achieved remarkable success in educating its own as well as the non-gay public about AIDS, it cannot continue to do so without significantly increased Federal assistance.

This highest risk of all risk groups, which has privately raised millions of dollars since 1981 to pay for education, prevention and services for all citizens, cannot continue to bear the burden virtually alone.

The Council would point out in conclusion, Mr. Chairman, that the current policy of administering Federal AIDS education and prevention programs in one Public Health Service agency and funding those programs by means of grants primarily to and through State public health departments, that may not be as effective as it could be.

More than one Public Health Service agency has statutory authority to conduct education programs; all have expertise to contribute. Moreover, any public or private organization, not just public health departments, that is capable of demonstrating expertise and ability, should be eligible to compete for a much larger proportion of Federal AIDS education and prevention dollars than is now possible.

Thank you very much, Mr. Chairman.

Mr. NATCHER. Thank you, Mr. MacDonald. You have made an excellent statement. We appreciate your appearance before the committee.

MONDAY, MAY 5, 1986.

HEALTH PROFESSIONS EDUCATION

WITNESS

CHARLES R. MODICA, CHANCELLOR, ST. GEORGES UNIVERSITY SCHOOL OF MEDICINE

Mr. NATCHER. Our next witness is Mr. Charles Modica. Come around, Mr. Modica, we will be pleased to hear from you.

Mr. MODICA. Mr. Chairman, my testimony is not necessarily related to the preceding testimony. I was originally scheduled to appear last week.

Mr. Chairman, and members of the subcommittee, I am pleased to appear before you today to speak about St. Georges University School of Medicine in Grenada, to discuss the issues of Federal support for students attending foreign medical institutions.

Since St. Georges was founded in August of 1976, nearly 800 students have graduated with degrees in medicine. Many have returned to the United States to practice in underserved areas, especially in inner city teaching hospitals that treat large numbers of low-income and indigent patient populations.

In fact, 80 to 90 percent of these residency positions are filled by graduates of foreign medical schools. There would be a significant problem in handling the patient load in many of these hospitals without foreign graduates.

The Journal of the American Medical Association, in its January 18, 1985 issue, reported St. Georges University School of Medicine students had the highest initial pass rate in the U.S. qualifying examination, higher than any other major foreign medical school in the world.

As each class at St. Georges finishes its second year of medical education, approximately one-third of that class transfers to U.S. medical schools to complete their education. This, too, represents the highest rate of any other foreign medical school in the world.

The list of hospitals, many affiliated with U.S. medical schools where most foreign-trained medical graduates have current residencies or have completed their specialties and subspecialties, includes almost every State in the Union.

St. Georges graduates are participating in 297 different training programs in 192 hospitals. St. Georges graduates are, for the most part, doing equal or better than many U.S. graduates. They are licensed and practice in almost every State.

Mr. Chairman, I mention the above points for several reasons, but mostly to dispel the myth that all students trained at foreign medical schools are second-rate.

Further, I want to make it clear that the same holds true for the institutions at which these students train. In this brief exchange, I hope to set apart St. Georges University School of Medicine from other institutions that have been accused of providing less-than-adequate medical education.

St. Georges, and other offshore institutions, have faced an organized effort by several U.S. medical societies and organizations to diminish the credibility of their graduates and to restrict the entry of those who have completed its educational process.

This organized effort includes restricting admissions to licensing examinations, refusal to issue licensing applications, restricting admissions to residency programs, and insisting on separate examinations from those given to U.S. medical students and graduates.

Could a primary reason for this be that when in 1979, St. Georges students who took the same examination that U.S. medical students took, scored so well compared to U.S. students?

Mr. Chairman, recently Congress has considered several proposals to reduce or eliminate Medicare Graduate Medical Education funding for the training of students educated in foreign medical institutions.

As you are most likely aware, the recently-passed budget reconciliation bill requires that a foreign-trained student pass the Foreign Medical Graduate Examination in the Medical Sciences to qualify for GME funding.

Although this examination is more difficult than the national boards that American students take, we at St. Georges believe this is a fair compromise, and does not arbitrarily discriminate against a student based solely on his/her place of education. We applaud Congress' discretion in making this provision fairer.

I come before you today to request that in your subcommittee's consideration of funding of Federal programs for health professions, and student aide, particularly Guaranteed Student Loans, that you take these aforementioned statements into consideration.

The Education Department has made several attempts to administratively cut off guaranteed student loans to U.S. residents attending foreign medical schools.

Should a proposal like this develop during your subcommittee's consideration, I am hopeful you will use the same discretion that the reconciliation conference yielded, a fair and equitable approach to the pursual of funds for all U.S. students, notwithstanding their choice of U.S. or foreign schools.

Further, while our students or institutions do not receive a great deal of the health professions resources allocated by your panel, we urge that you resist the overtures of select groups in organized medicine to discriminate against graduates of schools abroad, and St. Georges in particular.

In the event that there are cuts suffered, I would enter a plea for equality for all U.S. medical students, whether they study in the continental U.S. or are forced to study elsewhere.

While the medical monopoly of organized medicine criticizes the foreign medical schools, it is important for your committee to allow representatives of foreign schools to address these allegations on a continuing basis.

The American model of medical education, while clearly the most expensive in the world, may not be producing physicians of the quality of some foreign schools with less funding.

Thank you for the opportunity to present our views. I am happy to respond to any questions you may have.

Mr. NATCHER. Thank you very much, Mr. Modica. We appreciate your appearance before our committee at this time. How many students do you have at this time?

Mr. MODICA. We have approximately 1,000 students at St. Georges.

Mr. NATCHER. Thank you very much. We appreciate your attending this hearing.

MONDAY, MAY 5, 1986.

NIDDK

WITNESS

STERLING TUCKER, MEMBER OF THE BOARD, AMERICAN DIABETES ASSOCIATION

Mr. NATCHER. Our next witness is Mr. Sterling Tucker. Come around, Mr. Tucker. It is a pleasure to have you before the committee.

Mr. Tucker, you have been good for the District of Columbia. I say that to you frankly. You should have served as Mayor of the City, and you are still young enough that you still should serve.

You know as much about the new court building, the new library, the 26 or 27 school buildings, and six or seven library extensions, and smaller sections of our main library, as anyone in this city.

You have been good for the city. And we are glad to have you before the committee, and we will be pleased to hear from you.

Mr. TUCKER. Thank you very much. We were unhappy to lose you on the District side on Appropriations, but we know that the country needs you more here, and we are delighted that you are here today.

Mr. Chairman, I am Sterling Tucker, a member of the Board of Directors of the American Diabetes Association, and the Vice Chairman of the Government Relations Committee of the American Diabetes Association.

The American Diabetes Association has 58 affiliated associations and more than 200,000 lay and professional members. The ADA is very interested in and concerned about the budgets under your subcommittee's jurisdiction dealing with biomedical research, manpower training and health care services.

These programs are very important to the 11,000,000 individuals with diabetes and its complications. As you know, these complications affect the heart, kidneys, eyes and the nervous system.

Diabetes is the fifth leading cause of death by disease and is a major factor in disability in this country. It is also the leading cause of new blindness in adults. The economic burden of diabetes is approximately $14,000,000,000 annually.

Diabetes has a disproportionately significant impact on minority populations. For example, the prevalence of diabetes is 33 percent higher in the black population and the mortality rates related to diabetes for Native Americans is more than twice that for the general population.

Programs of the National Institutes of Health have produced many important developments in recent years regarding diabetes. Those programs already have produced or will produce major savings in health care payments and disability payments.

One, the development of laser therapy for the treatment of diabetes retinopathy has already saved in medicaid and welfare payments three times the research funds spent for the development of that treatment.

Two, the Diabetes Control and Complications Trial has passed through its feasibility stage and is now at full operation. The objective of the DCCT is to establish whether strict control of blood glucose reduces the incidence of complications arising from diabetes.

Approximately 1200 individuals will be studied during the course of this clinical trial. The potential savings from knowledge gained about the effectiveness of strict control in treating Type I diabetes and the prevention of eye disease and other complications is conservatively estimated at $350,000,000 annually by the NIH.

The savings are likely to be more than that, since such knowledge would be applicable to the treatment of Type II cases also.

Three, research related to transplantation of pancreatic islet cells has been expanded in recent years. Currently, two centers are doing clinical studies on this matter, and some of the results are quite positive.

Let me just mention a few of the research activities that will not be undertaken in fiscal year 1987 under the President's budget because of its extremely low dollar recommendation.

One, there is at least one approved but unfunded diabetes and endocrinology research center that will not be funded. The number of such centers has remained stable for many years. The program has been very successful in stimulating new developments in research and translating that research into practice.

Two, a very important study with enormous potential for cost-effectiveness, dealing with early intervention in the treatment of those with diabetes who have kidney disease, will not be supported. Approximately 30 percent of all medicare recipients who are undergoing kidney treatment and dialysis have diabetes.

Finally, the Diabetes Institute had intended to undertake a major initiative with regard to health care for minority populations with diabetes and will not be able to do so if the President's budget is adopted.

If the President's budget were adopted, the Diabetes Institute will only be able to fund less than 25 percent of all approved research applications, the lowest rate of any Institute.

For NIH as a whole, as you know, the numbers of research grants will be reduced by 1,000 and the numbers of trainees to be supported in fiscal year 1987 will be 1,500 fewer than in fiscal year 1985.

We, along with many other groups, recommend a budget for the NIH which would be approximately $6,100,000,000 in fiscal year 1987.

We also urge the subcommittee to expand NIH funding of the biomedical research support program for minorities.

With respect to NIDDK, we recommend a budget of approximately $500,000,000. The budget would enable the Institute to fund about 637 new grants and to undertake those initiatives which I have referred to before.

The President's budget for fiscal year 1987 proposes to eliminate the $5,000,000 program of support to State health departments and retain only the in-house staffing aspect of the program.

This proposal is similar to ones made in the fiscal year 1985 and fiscal year 1986 budgets. We urge the subcommittee to at least continue the Diabetes Control Program at its current level of $7,500,000.

We would also urge that the subcommittee support the CDC approach of targeting programs on specific complications and urge the CDC to focus the program on those minority populations where the prevalence of diabetes is so great. Language in the committee report to this effect would be very helpful.

The President's budget recommends the elimination of support for most all health manpower training. One such program of great importance to our constituency is the training of health professionals to serve minority populations.

As noted in the Secretary's Task Force Report on Black and Minority Health, minority populations have excessively high rates of diabetes and the complications of that disease fall much more heavily on those groups.

We also do not have sufficient professionals serving the minority population. In order to assure adequate and up-to-date health care for those populations, we believe that such manpower training, particularly for students from disadvantaged students. We strongly recommend that the program be expanded in fiscal year 1987 over the fiscal year 1986 level.

Mr. Chairman, thank you, sir.

Mr. NATCHER. As I said before, you have been good for the District of Columbia, Mr. Tucker, and you will like the bill that we bring out.

[The statement of Mr. Tucker follows:]

TESTIMONY
OF
STERLING TUCKER
FOR THE
AMERICAN DIABETES ASSOCIATION

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR, HHS, AND EDUCATION

ON
APPROPRIATIONS FOR THE DEPARTMENTS OF
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND
RELATED AGENCIES

MAY 6, 1986

Introduction

Mr. Chairman: I am Sterling Tucker, a member of the Board of Directors of the American Diabetes Association (ADA) and the Vice Chairman of the Government Relations Committee of the American Diabetes Association. The American Diabetes Association has 58 affiliated associations and more than 200,000 lay and professional members. The ADA is very interested in and concerned about the budgets under your Subcommittee's jurisdiction dealing with biomedical research, manpower training and health care services. These programs are very important to the 11 million individuals with diabetes and its complications. As you know, these complications affect the heart, kidneys, eyes and the nervous system. Diabetes is the fifth leading cause of death by disease and is a major factor in disability in this country. It is also the leading cause of new blindness in adults. The economic burden of diabetes is approximately $14 billion annually.

Diabetes has a disproportionately significant impact on minority populations. For example, the prevalence of diabetes is 33% higher in the black population and the mortalilty rates related to diabetes for Native Americans is more than twice that for the general population.

Thanks to you Mr. Chairman and your Subcommittee, we have made great strides in dealing with the problem of diabetes, particularly through programs which receive appropriations from this Subcommittee. For example, approximately $190 million was budgeted and expended in Fiscal Year 1985 by NIH for research related to diabetes. The Centers for Disease Control (CDC) support a $7.5 million program to prevent the complications of diabetes. In addition, major health service programs are significant for the care of those with diabetes; the Maternal and Child Health Program is particularly important because of the services it provides to women with diabetes and their children.

FY 1987 Budget Proposals

National Institutes of Health

Programs of the National Institutes of Health (NIH) have produced many important developments in recent years regarding diabetes. Those programs already have produced or will produce major savings in health care payments and disability payments. (1) The development of laser therapy for the treatment of diabetic retinopathy has already saved in Medicaid and welfare payments three times the research funds spent for the development of that treatment. (2) The Diabetes Control and Complications Trial (DCCT) has passed through its feasibility stage and is now at full operation. The objective of the DCCT is to establish whether strict control of blood glucose reduces the incidence of complications arising from diabetes. Approximately 1200 individuals will be studied during the course of this clinical trial. The potential savings from knowledge gained about the effectiveness of strict control in treating Type I diabetes and the prevention of eye disease and other complications is conservatively estimated at $350 million annually by the NIH. The savings are likely to be more than that since such knowledge would be applicable to the treatment of Type II cases also. (3) Research related to transplantation of pancreatic islet cells has been expanded in recent years. Currently, two centers are doing clinical studies on this matter and some of the results are quite positive. (4) Research supported by the National Institute of Child Health and Human Development has enabled progress to be made in the treatment of pregnant women who are afflicted with diabetes and has resulted in reduced rates of disabling conditions among the children of such women. The health care and disability payments for the disabled children who have been born of mothers with diabetes are extraordinarily high. While we have not calculated the savings from such advances we know they are substantial.

The President's budget for the National Institutes of Health and particularly for the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) will set back this progress enormously. Let me just mention a few of the research activities that will not be undertaken in Fiscal Year 1987 under the

President's budget because of its extremely low dollar recommendation. (1) There is at least one approved but unfunded diabetes and endocrinology research center that will not be funded. The number of such centers has remained stable for many years. The program has been very successful in stimulating new developments in research and translating that research into practice. (2) A very important study with enormous potential for cost effectiveness, dealing with early intervention in the treatment of those with diabetes who have kidney disease, will not be supported. Approximately 30% of all Medicare recipients who are undergoing kidney treatment and dialysis have diabetes. (3) Equipment and instruments for research are antiquated and we lag behind in their quality. A major program to improve the equipment and instruments used by the scientists who deal with diabetes and endocrinology will not be supported. (4) An initiative to obtain and distribute human tissue for use in biomedical research and islet cell and pancreatic transplantation will not be undertaken. (5) Finally, the Diabetes Institute had intended to undertake a major initiative with regard to health care for minority populations with diabetes and will not be able to do so if the President's budget is adopted.

If the President's budget were adopted, the Diabetes Institute will only be able to fund less than 25% of all approved research applications, the lowest rate of any Institute. For NIH as a whole, as you know, the numbers of research grants will be reduced by 1,000 and the numbers of trainees to be supported in FY 1987 will be 1,500 fewer than in FY 1985. Based on NIH estimates, the minimum acceptable award rate for approved research project grants is 50 percent. If that award rate is not maintained, the resulting reduction in the numbers of research grants and trainees will set back science generally and will discourage young scientists from careers in biomedical and behavioral science. There will also be a loss to science of many existing biomedical scientists who cannot get support for their research.

The American Diabetes Association Proposal

We, along with many other groups, recommend a budget for the NIH which would be approximately $6.1 billion in FY 1987. Such a budget would support the same level of research activity in FY 1987 as undertaken in the current year if the FY 1986 appropriation had been implemented, including about 6100 new grants at full funding. It would provide for the full funding at peer review recommended levels of research grants for all programs. Training and career development programs could be adequately supported at slightly above current service levels.

We also urge the Subcommittee to expand NIH funding of the biomedical research support program for minorities.

With respect to the NIDDK, we recommend a budget of approximately $500 million. That budget would enable the Institute to fund about 637 new grants and to undertake those initiatives which I have referred to before. The budget would enable full operation during Fiscal Year 1987 of the diabetes complications clinical trial. Islet cell and pancreatic transplantation research would also be adequately supported.

We think this level of funding is absolutely essential in order to simply continue current progress and we would urge that the Subcommittee provide the recommended funds for the National Institutes of Health and the Diabetes Institute.

We believe that our proposal would provide NIH with a balanced program of research grants, centers, training, clinical trials, and intramural research. We urge that NIH have sufficient flexibility to support such program balance whatever the level of appropriation provided.

2. Centers for Disease Control

The Centers for Disease Control budget currently supports the Diabetes Control Program (DCP). That program is supported at $7.5 million of which $5 million is provided to state health departments for program activity. It should be noted that the States with DCP programs often provide substantial state investment in the program. The federal money induces that investment. The Subcommittee has assisted in protecting this program from elimination in prior years. The program has been very cost effective. The DCP supports 20 State programs; an additional 10 one-year programs were started last year. The program has recently focused upon supporting preventive services related to specific complications of diabetes such as eye disease or pregnancies with complications of women with diabetes. Savings produced by this program are substantial and result from reduced hospitalization, reduced surgery rates and reductions in morbidity and mortality. This is an example of a program in which research results are cost-effectively translated into practice. Examples of such programs which have similar cost savings are South Carolina, Maine and Kentucky.

The President's budget for FY 1987 proposes to eliminate the $5 million program of support to State health departments and retain only the in-house staffing aspect of the program. This proposal is similar to ones made in the FY 1985 and FY 1986 budgets. We urge the Subcommittee to at least continue the Diabetes Control Program at its current level of $7.5 million. We would also urge that the Subcommittee support the CDC approach of targeting programs on specific complications and urge the CDC to focus the program on those minority populations where the prevalence of diabetes is so great. Language in the Committee Report to this effect would be very helpful.

3. Health Manpower Training

The President's budget recommends the elimination of support for most all health manpower training. One such program of great importance to our constituency is the training of health professionals to serve minority populations. As noted in the Secretary's Task Force Report on Black and Minority Health, minority populations have excessively high rates of diabetes and the complications of that disease fall much more heavily on those groups. We also do not have sufficient professionals serving the minority population. In order to assure adequate and up to date health care for those populations, we believe that health manpower training, particularly for students from disadvantaged backgrounds, is essential. We need to train more health professionals who will provide service to minority populations. The President's budget for FY 1987 would eliminate the program of assistance to disadvantaged students. We strongly recommend that the Program be expanded in FY 1987 over the FY 1986 level. This expansion would be one way to implement the objectives of the Secretary's Task Force Report on Black and Minority Health. We would urge that the Committee suggest to the Department that initial emphasis in some of its curriculum and special projects activity be placed upon the training of minority health professionals in the diagnosis and treatment of diabetes and related disorders.

Mr. Chairman, we are making a number of of other recommendations about many appropriations programs, some of which are not in the jurisdiction of this Subcommittee. We would like to submit that material for the record. I would be very happy to answer questions about diabetes and the programs which we hope will enable us to find a cure or to better treat those with diabetes.

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MONDAY, MAY 5, 1986.

SPINAL CORD REGENERATION

WITNESS

DR. J. HARLAN DIX

Mr. **NATCHER**. Our next witness is Dr. Dix. Come around, Dr. Dix, we will be pleased to hear from you.

Dr. **DIX**. Thank you, Mr. Chairman.

I want to thank this committee and Congressman John Seiberling for allowing me to submit my data and summarize my thoughts on spinal cord injuries. Let it be said at the outset that I came here with a distinct and heavy bias.

Three years ago, our youngest son, Doug, sustained a spinal cord injury which resulted in his being paralyzed from the neck down. He was midway through his studies in business journalism at William and Mary College, looking forward to joining our newspaper family when it happened.

I am not going to belabor the bleakness that can smother a close-knit family when such a thing happens, but three years ago the dogma prevailed that spinal cords, once injured and broken, did not regenerate. It was easy for us to get the picture. This was it. I became impressed quickly with two main themes: Hopelessness and expense.

Well, we all bled for a while, but then, to be succinct, we regrouped. Doug is an exception, but within one year he was in his own apartment, attending Kent State University in Ohio, having switched his major to accounting.

He is now in his own home near the university, making high marks in his major, still paralyzed, turning pages with a mouth stick, running a wheelchair with his chin, under the surveillance of ever-present attendants.

Of the two main themes, the expenses continue, but the hopelessness has changed. We have great scientists in the world, and a lot of them are focused in the United States and Canada, and many are right here in the NIH.

Three years ago, scientific interest in central nervous system regeneration following injury was minimal at best, but for many reasons, including, one, better understanding of neurobiological processes at the cellular level; two, development of transplantation techniques; three, isolation and genetic clarification of nerve growth factor.

And so many other legitimate factors, that today it has become the perception of many first-class neuroscientists that we have reached a brink, a point at which integrated, full-scale efforts can now assume a more clinical, pragmatic approach and go for the brass ring, much like we did when insulin was discovered.

We didn't fully understand diabetes at the cellular level, but injections of insulin stopped the gradual slide down the hill to a miserable death for the insulin dependent diabetic and returned them to the working, taxable pool.

We still don't know the exact cause of diabetes, but that is being worked out on its own time. The problem of spinal cord injury cure has become not so much a question of basic science anymore as it has become a question of administration.

So now, set aside my bias and all the Dougs of the world, and let's consider some fiscal sense.

Not even taking into consideration central nervous system conditions such as strokes, spina bifida, Parkinsonism, tumors and diseases which leave one-sixth of the U.S. paralyzed at variable levels which will benefit from CNS regeneration, conservative estimates indicate that spinal cord injuries alone cost society some $2,000,000,000 each year.

More than 10,000 are added to the list every year, about one injury every 40 to 50 minutes. They occur in people averaging 18 years of age. Excellent medical care does not allow them to die.

If we go on as we are, nickle-diming our way, and we have sold a lot of T-shirts and balloons in the past three years, funding projects so that brilliant scientists can spend only about 10 to 20 percent of their time in an uncoordinated, science-for-science-sake effort, someone will get it together, probably in 15 to 20 years.

Well, my bias doesn't have that kind of time and I would hope that people with fiscal sense would perceive the benefits of returning these souls to the productive work pool where taxable income is generated rather than absorbed in medical care, nursing necessities and technological gadgetry.

I have therefore suggested three points for your general consideration: One, continue basic research under the auspices of the NIH as outlined under the Health, Research and Extension Act of 1985.

Two, at this time, join the several recent discoveries and direct a mini-moon shot effort toward the target of cure. This would not be a departure from understanding the scientific principles at the cellular level, but rather a subtle shift to effecting a change at the walking level.

Three, such a pragmatic approach should receive ad hoc funding of $1,000,000,000 which must be considered as an investment rather than a subsidy and should be guided by a committee, preferably currently involved and charged and monitored to spend 100 percent of its time affecting a cure.

Thank you very much.

Mr. NATCHER. Doctor, we appreciate your appearance before our committee. You mentioned Mr. Seiberling's name. John Seiberling is one of the good members in the Congress. We are going to miss John Seiberling.

[The statement of Dr. Dix follows:]

PREPARED FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION, HONORABLE WILLIAM H. NATCHER, CHAIRMAN.

BY: J. HARLAN DIX, M.D.

REPRESENTING: SELF

DATE: APRIL 23, 1986, 2:55 P.M.

I come here with a heavy bias. My name is Harlan Dix and I'm a practicing physician in Akron, Ohio. My wife and I have seven children - all great kids - and we lead the good, Midwestern lifestyle. Three years ago our youngest son, Douglas, now 25, sustained a spinal cord injury while competing with fellow students on the campus of the College of William and Mary. He was midway through his studies in business journalism when his world stopped. He was paralyzed from the neck down. He forfeited much. Things came with difficulty, his chest movements responded only to the mechanical respirator. He was unable to feel or even sense position, unable to wipe his face or challenge a fly that landed on a salty tear.

Three years ago we were told, "That's it folks." I remember being told that he wouldn't breathe on his own and that the most we could expect from body movement would be a possible shrug of his shoulders. That would be "max," they said. I remember the word "max." We doctors use such clever jargon.

Within one year Doug was taking a computer course at Kent State University. Still paralyzed from the chest down, he was extremely spirited from the neck up. He is on target toward completing a course in accounting, maintaining very high averages. He explains, "I can't move my body yet, but I can certainly use my brain." I am admitting to you now that the first post-injury year can best be described by using the word despair. We have been sustained through all this by Doug's unconquerable soul. He has been able to sustain us and his teachers and his ever-present attendants who take notes for him and who take care of his very personal needs. He maintains mobility with a wheelchair which responds to signals generated by movements of his chin and he is able to use a mouth stick to turn his pages and run his computer, etc. Doug has been able to do all this for two main reasons: Firstly, he is made of the right stuff. Secondly, he never really accepted this "max" stuff.

At the time of the injury I was guided by the lights of famous old physicians who had been kind enough to explain that the spinal cord axons (the wires carrying impulses from the brain down through the vertebrae and relaying messages to the muscles of the body), once injured, do not regenerate. Injuring these little wires of the spinal cord by the shearing action of a back injury in which one vertebra is dislocated from its adjacent vertebra could be compared with crushing, bending and breaking the transatlantic telephone cable. Electrical impulses are interrupted and even if some wires persist unbroken, the injury creates short circuits resulting in the dialing of wrong numbers. A bad situation. The first year was bleak and black and filled with despair, but when we were able to regroup and make a few course adjustments, we began to see flickers of light generated throughout the world suggesting that the spinal cord could regenerate, given the right environment. (See initial fund request effort enclosed.) We became interested in and influenced by a group of prestigious scientists working mainly in our medical schools in the United States and Canada and organized into a Spinal Cord Society. Through the efforts of government sponsored projects and through efforts of bright scientists throughout the land, there had truly been a knowledge explosion resulting in the generation of scientific data which has caused many chapters in scientific textbooks to be rewritten. The axons in the spinal cord can regenerate, given the right environment and the proper stimulating substances. Even incomplete generation, in which enough axons can be allowed to grow through the injured area, is functionally acceptable. The plasticity of the central nervous system permits the wires to communicate with one another and with the influence of nerve growth factor and appropriate enzyme molecules, targets are sought out and joined. Combined with functional electrical stimulation which is being applied to humans as of this year, a stage has been set which has all the analogous properties of a spectacular and smashing Broadway hit. Such enthusiasm is supported by many laboratories throughout the country. Dr. Carson, in "A Message from the President of the Spinal Cord Society," stated, "It is now evident the dogma of hopelessness is false. Spinal cord injury and its devastating effects can be vastly alleviated and even cured if the proper effect is focused upon them." The term "proper effect" is key.

We have our foot in the door which leads to the room which has all the proper furnishings of a cure for the spinal cord injured. Again, let me say that this has come about because of combined efforts generated from the private sector and because of governmentally funded scientific research projects which have emanated from scientific contributors and human services contributors such as the NIH and the NIH Subcommittees. These are the subcommittees before whom I am now being allowed to testify. My concern, which is based on an admitted bias, is that if we continue at a level of studying regeneration and funding and refunding projects to do basic research in the regenerative processes in a sort of art for art's sake approach; if we stand here with our foot in the door studying the intricacies of the lock, the way the knob turns and the way the hinges fit and exactly how the door hangs in relationship to the contour of the jamb, a period of time will be consumed that will preclude Doug and me from going back to that first hospital in Virginia, walking up to Dr. "Max" and turning dual precision cartwheels to the accompaniment of clapping and whistling from his mother, brothers and sisters. The way we are forced to pick and choose and scrimp in order to direct what we have into a more clinical arena will not produce results for up to 20 years. With my bias, therefore, I am naturally more inclined to see research targeted toward a more pragmatic approach, much like the approach to the problem and control of diabetes years ago. Diabetes was a devastating disease. Many people, as a result of their sugar/insulin imbalance, would gradually slip into a diabetic coma and die. Doctors Banting and Best in Canada opened the door, found insulin, and started to treat this sickness. Victims got well. They returned to the work pool. We still don't know the complete story at the cellular level of this complex illness. The pragmatic approach, however, has allowed us to control what would otherwise be a devastating and tragic situation while we still chip away at the molecular changes at the cellular level.

It is perceived that we are at the threshold of a similar situation in spinal cord injuries. The discipline of neurophysiology and neurobiology has invaded every medical school in the country. Central nervous system regeneration has been demonstrated. Transplantation of nerve tissue and cultured neurons and supporting cells has been accomplished. Functional electrical stimulation is well under way. Adjunctive efforts in the fields of immunology, polymer chemistry and other very sophisticated scientific subspecialties have brought us to a veritable brink. A point at which we ask not how we are to invent a cure, but rather how are we going to execute a cure. I have been impressed with the zeal and dedication of organizations in supporting such a thrust. (See Spinal Cord Society research projects.) It is my perception that with continued efforts such as these, the complex parts of the cure can be put together within 18-20 years. Here comes my bias again. Gentlemen, I ain't got 20 more years. I have to see my boy walk before then. Therefore, let's swing about and take another tack.

Set aside my bias. From the standpoint of the United States government, tremendous fiscal sense is made. From the government's very conservative figures, it is estimated that spinal cord injuries cost society some 2 billion dollars every year. Approximately 10,000 new spinal cord injuries occur each year. The majority of injuries occur in people averaging 18 years old. Excellent medical care does not allow them to die. To spend a billion dollars to effect a cure makes more sense than spending 2 billion dollars each year. We also know that 10,000 new spinal cord injuries are being added to the totals every 12 months. Add more than one victim to every hour of every day of every year. We end up supporting attendants, buying wheelchairs and catheters, treating bedsores and pneumonia and urinary tract infections, inventing new stool extraction methods, tilt tables, and electrical gadgetry. Hollywood films somebody walking across the stage accepting a diploma. This is poor business and exploitation when the real regenerative process is within our reach. There are so many bright young scientists out there who are capable, and, if the funds are properly directed by somebody who is properly motivated, you'll do away, not only with the 2 billion (and counting) dollars expense each year but you will return the patients to the working and taxable pool. Please make note that I'm talking only of the spinal cord injured. The spinoffs from such an accomplishment involve victims of strokes, brain damage, degenerative diseases and neurological disorders which affect 1/6th of the population of the United States.

Such an effort requires undivided attention. Men like Dr. Silver at Case Western Reserve, in conjunction with Dr. Yannas from MIT, stand ready to go with transplantation of embryonal astrocytes and a polymer bridge in the spinal cord injured area and many, many others who have brought us to this threshold, cannot be allocating only 10% of their time at the helm of a specific project and expect the efficient outcome that would result from a 100% effort. Undivided attention from people like this requires subsidy. But this is more than subsidy. Good businesses invest money so that profitable income is generated. Such investment, designed to reduce the financial drain of our country from 20 years to 3 years, cannot be generated by even the most courageous efforts of the concerned people in the private sector. A mini-moonshot is needed. I feel that the fiscal sense of a spinal cord cure, following which people can use their hands and bodies and walk to a productive work pool and generate income rather than absorb it in medical care and technology, is obvious. What a fantastic investment.

I would therefore summarize with the following suggestions:

1. Continue basic research under the auspices of the NIH as outlined under the Health, Research, & Extension Act of 1985.

2. At this time, join the several recent discoveries such as transplantation of embryonal cells, use of nerve growth factor, functional electrical stimulation, bridging of scarred areas with polymer supporting molecules and other promising discoveries as determined by a panel of experts, directing a mini-moonshot

toward the target of cure. This would be a departure from the belabored, albeit important, understanding of the scientific principals at the cellular level to a more pragmatic effort of affecting a change at the walking level. Functional electrical stimulation alone, embryonal cell transfer alone, nerve growth factors, polymer bridging, tropic factors, antibodies and anti-anti bodies, laser surgery, nerve grafting are interesting and scientifically fascinating, but left unto themselves are functionally futile. Interaction of all disciplines is essential. Such an intense approach should receive ad hoc funding of one billion dollars and should be guided by a committee involved specifically in affecting a cure. This would be a happy and sensible fiscal conclusion to a devastating condition.

J. HARLAN DIX, M.D., INC.
444 NORTH MAIN STREET
AKRON, OHIO 44310

TELEPHONE 434-7065

OUR INITIAL LETTER IS AS FOLLOWS:

October 4, 1984

Dear Family and Friends:

When our youngest son Doug was six and I was well into my forties, we could fix anything fixable. Things that were not fixable, we replaced. Guns, bikes, radios, bloody noses, hernias and engines, ad infinitum. Christmas toy assembling was a specialty. Many parents joked about never buying anything "to be assembled." Our kinds reveled in it. There was nothing flyable we couldn't make fly. One dark but clear night there was a half moon. It looked as if the Great Being had taken a megamachete and sliced it cleanly in half. On the way from the car to the house our son looked up and said, "Mommie look - the moon is broke." "That's all right" he soon added, "Daddy will fix it." It was a great era for us. Captains of the Ship, King of the Roost, Lord and Master, and all that sort of thing. Even as they became adults, our young charges didn't have to see doctors because we would take care of most complaints or find a friend of ours who could.

One year and six months ago, when Doug sustained a spinal cord injury with associated loss of function from the neck down, there were no initial doubts in our mind but that he would be 100% O.K. As time went on it gradually became apparent that we were not fixing it. We stared at the world in disbelief. A lot of good things did happen, however. He regained the ability to breathe on his own and some of his shoulder muscles came back. Even with these very few functions, within a year Doug was living on his own, except for an ever present attendant, in an apartment in Kent, Ohio taking a computer course at Kent State University. But this had to be just the first period of a three period match.

The second period of the match took place and is continuing to take place in an arena of rehabilitation centers; bleak places indeed, presenting as a composite of wheelchairs, communication gadgetry, cathodes and catheters, weights, tilt tables, eoectronic muscle movers and computerized everything. Most spinal cord injury victims are living out normal life expectancies. They figure that most mechanized existences can be accomplished at an expenditure of 1½ million dollars per patient and it is still pretty bleak.

In fact, there are times when we look at one another, deep in the pit, when the arms won't move and the toe won't twitch, and a fly lands on a forehead unchallenged, and about all we can manage is to thank God for an unconquerable soul. But we wish we could fix it. We do, we do, we do.

The third and most anticipated period is the one which I am now addressing and the one which I think is so exciting. It takes me back to the days when we could fix anything. There have been tremendous breakthroughs in molecular biology, biochemistry, immunology, genetic chemistry, electrical fields and basic research techniques, all of which is being integrated and applied to neurobiopathology by bright, young men. Cold laser beams are melting away scars. Spontaneous regeneration of the central nervous system is being induced by the creation of micro-lesions. Nerve growth factors are demonstrated to be distinct enzymes. Electrical fields are being created and applied to nerve axon regrowth. Problems with the central nervous system such as multiple sclerosis, strokes, degenerative diseases as well as injuries are about to reap the benefits of more basic understanding.

The answer to spinal cord regeneration is man is somewhere out there. It must be brought together. There is no doubt but that this can be accomplished. It will take our efforts converted into money and reconverted into continued pure research that will bring us the answer soon. I know it can be done. It can be fixed. It can, it can, it can.

Please join us in this great venture.

Janet and Harlan

JHD:cmm

SCS RESEARCH PROJECTS

PRESENT PROJECTS CONTRACTED BY SCS (1984-85)

Regeneration Through Surgery, Hypothermia, and Drug Therapy ***$60,810***

Two projects at McMaster University. Pioneering experiments in new surgical techniques to control axonal regeneration are being combined for the first time with experiments in hypothermia.

Identification of Regeneration Inhibitors in the CNS ***$25,060***

This project at Stanford University is the first of its kind designed to identify and overcome specific chemical inhibitors of nerve regeneration.

Nerve Growth Factors in the CNS ***$100,000***

A project at Washington University, St. Louis, to identify specific nerve growth factors in the CNS and isolate them for direct injection into the nervous system to produce regeneration.

Electrically Enhanced Regeneration in the CNS ***$27,630***

The purpose of this research at Purdue University is to use controlled electrical currents for the first time to directly influence regeneration in the mammalian spinal cord.

Artificial Spinal Bone Substitutes ***$65,000***

The first attempt to devise artificial spinal bone substitutes has been initiated at the University of Pittsburgh by SCS. The ultimate goal is vastly improved spinal stabilization via complete vertebral replacement.

Nerve Graft Reconstruction of Spinal Cords ***$50,000***

This project at Colorado State University combines improved surgical methods with grafting techniques to see if transplanted cells may successfully bridge an injury site in the spinal cord.

Computerized Walking ***$27,000***

First popularized by SCS grants, the most advanced project is that at Case Western Reserve University and the Cleveland VA Medical Center. Completely paralyzed human subjects in clinical trials are now able to walk, climb stairs, and achieve balance via computerized electrical stimulation (FES).

Clinical Trials in Re-establishing Sexual Function in Paralyzed Man ***$7,000***

Clinical trials now underway at the Spinal Center at the University of Minnesota are evaluating subcutaneously administered cholinomimetic agents in re-establishing sexual function in human males.

Antiserum-Induced Regeneration in CNS Lesions ***$43,340***

The first project of this type seeks to identify and use control mechanisms responsible for antiserum-induced regeneration with the ultimate eventual aim of human applications. University of Alabama in Birmingham.

Adhesion in CNS Regeneration ***$75,000***

Neither nerve growth factor nor nerve growth inhibitors alone or together are sufficient to determine axonal regeneration. A properly adhesive surface, or "bridge" is also required. This project is aimed at developing such a bridge for insertion into lesioned spinal cords. University of Minnesota.

The Role of Magnetic Resonance Imaging in Spinal Cord Injury ***$6,231***

In order to better determine the need or contraindication for spinal surgery a 6 month series of experiments will determine the degree of cord damage after injury prior to any operation. University of Minnesota.

1979-81	Drug therapies to reverse SCI	New York University	$32,000
1981	Omentum Transplants	Dartmouth College	$20,000
1982	Embryonic Grafts	Colorado State University	$10,700
1982	Computerized Walking	Wright State University	$91,000
1983	Computerized Walking	Case Western Reserve & the Cleveland VA Medical Center	$21,000
1984	Artificial Bone Substitutes	University of Pittsburgh	$48,700

MONDAY, MAY 5, 1986.

TUBEROUS SCLEROSIS

WITNESS

DR. BENNETT LAVENSTEIN, MEDICAL ADVISOR, TUBEROUS SCLEROSIS ASSOCIATION OF AMERICA, INC.

Mr. **NATCHER**. Our next witness is Dr. Lavenstein. Come around, Doctor, we will be pleased to hear from you at this time.

Dr. **LAVENSTEIN**. Mr. Chairman and members of the subcommittee, my name is Dr. Bennett Lavenstein, Assistant Professor of Neurology and Pediatrics, Georgetown University School of Medicine, and Medical Consultant to the American Tuberous Sclerosis Association.

I met Mr. Conte in another setting, and it is appropriate after hearing the testimony of the other witnesses that his resolution to make the period 1986 to 1996 the decade of the brain, in terms of study, funding for the neurosciences seems most relevant.

We are very pleased to be here today and thank you for the opportunity to be heard. As you know, tuberous sclerosis is a serious inherited disorder that may result in severe mental retardation, epilepsy, multiple physical handicaps, tumors in any vital organ and characteristic skin abnormalities.

Recent studies have indicated that the prevalence of TS is 1 in 5,000 to 1 in 10,000. It is believed that many additional individuals have this disorder with minimal manifestations. Nevertheless, these mildly affected individuals can pass on a severe form of this disease to their children.

In past years, the ATSA has made specific requests to this committee directed toward tuberous sclerosis research. We are here again to continue the momentum that has been established for tuberous sclerosis research.

The first tuberous sclerosis research workshop, which was held on April 13, 1984, and cosponsored by NINCDS and ATSA, was enthusiastically received by approximately 140 attendees.

Many other leading scientists and clinicians who were unable to attend in person have since requested copies of the proceedings of the workshop.

The TS research community is excited about the workshop, for it has identified a number of promising research directions which are fully feasible at this point in time subject to available funding.

Material from the workshop is coming close to publication. The publication of that effort will provide new impetus to the researchers who were involved in the workshop, as well as others worldwide who were unable to attend.

Another benefit of such publication will be an increase in public awareness of tuberous sclerosis.

Following the workshop, a letter was sent to leading investigators in tuberous sclerosis and related fields inviting them to participate as members of the ATSA Scientific Advisory Board.

The Advisory Board will participate in an ongoing review and development of approaches to the diagnosis, management, treatment and prevention of this disease. The letter was enthusiastically received; we have attached a list of the members on this important Board.

Dr. Frederick Bowman of the Harvard-MIT Division of Health Sciences and Technology, and Dr. Edgar Y. Oppenheimer, Professor in Pediatrics and Neurology at Boston University School of Medicine, Co-Directors of the TS research workshop, have been working together to establish the groundwork for the national case registry and for the development of a multiproject consortium research application in the basic science of tuberous sclerosis.

It became very apparent during the recent research workshop that many of the basic scientific tools which are needed to carry out investigations of the basic mechanisms in TS are available and have already been applied to other neurological diseases.

Our immediate goal therefore is to apply these existing techniques to TS. In order to accomplish this goal, case material must be made readily available to the research scientists and to clinicians.

In this regard, it was the consensus of the workshop that the establishment of a nationwide tuberous sclerosis registry should be given highest priority.

We feel that a nationwide case registry should be established in conjunction with ATSA. The cost of initiating and running a viable TS case registry program is estimated to be approximately $250,000 for the first year.

This cost includes correspondence with tens of thousands of physicians and health care providers who may be in contact with individuals with TS. Ethical concerns such as informed consent, confidentiality and access to the information in the case registry are being addressed.

Following the establishment of the case registry, Doctors Bowman and Oppenheimer plan to develop a multiproject consortium research application in order to facilitate the conduct of basic science research in TS.

The multiproject application will include a clinical core which will serve to gather clinical specimens for duty by the various basic science research investigators, pathologists, biochemists, cellular and molecular biologists and clinical and biochemical geneticists.

The ATSA Scientific Advisory Board will be used as resource individuals in the development of the clinical core. This is the first step in gathering the prerequisite expertise for the multiproject consortium effort.

Investigators in the clinical core will make extensive use of the cash registry to obtain clinical materials. Adequate facilities to coordinate the activities of the clinical core such as preserving and disseminating tissue specimens for evaluations are needed.

A conservative estimate of the cost of mounting the multidisciplinary consortium, including the clinical core, is approximately $1,300,000 per annum. The funding would pay for the clinical core, as well as fund six to eight separate basic science research projects.

The total amount of support which we feel is needed to set up a cash registry and to effectively utilize and mobilize existing investigators conducting relevant research is $1,500,000 to $2,000,000 per year.

We have learned from the research workshop that there is widespread interest in TS among scientific investigators of highest quality. We now exist in a unique point in time where there is both a developing momentum and a confluence of interest among investigators from different disciplines, health care providers and Members of Congress.

We want to build on this momentum and continue our work.

The ATSA strongly recommends a budget increase over the annual rate of inflation to NIH/NINCDS. A budget increase over the annual rate of inflation would permit NINCDS to maintain its current research efforts while affording new and promising initiatives, like tuberous sclerosis, the opportunity to seek and gain funding through HHS/NIH/NINCDS.

In conclusion, we would like to remind this committee that there are thousands of families throughout the United States coping with this tragic disease. The consequences for TS families are monumental: Emotionally, physically and financially.

Emotionally, marriages are greatly stressed and often end in divorce; unaffected brothers and sisters are denied a normal family environment.

The undiagnosed TS child is usually subjected to excessive child abuse, both physically and psychologically, by parents, family members, professionals, and peers who do not recognize that he/she is critically ill.

Victims and their families have desperate unmet needs. The physical demands of 24-hour-a-day in-home care for such children defies adequate description. Financially, the effect can be catastrophic.

The impact of tuberous sclerosis for the patient is devastating and it is life-long. TS patients require a wide variety of services, i.e. drug, physical, occupational and speech therapy, to name a few.

Identified TS children that grow to adulthood seldom have the ability for self-support and/or self-care. Clinical facilities that specialize in tuberous sclerosis care and treatment are non-existent.

If we are to help tuberous sclerosis, this picture must change. Research is the only hope to resolve the enigma that is TS. Additionally, once initiated, meaningful research programs will have many positive fringe benefits, not the least of which is to offer hope to a desperate group of sick and afflicted Americans.

Again, we wish to thank this committee for the opportunity to be heard on what we consider a most urgent concern. I would be very happy to answer any questions.

[The information follows:]

american tuberous sclerosis association

SUMMARY

The following recommendations are requested by the American Tuberous Sclerosis Association (ATSA):

1. That a budget increase over the annual rate of inflation be allocated to NIH/NINCDS.
2. That a minimum of $250,000.00 be allocated for the establishment of a nationwide Tuberous Sclerosis registry.
3. That a minimum of 1.5 million dollars per annum be allocated for the development of a Tuberous Sclerosis Multiproject Consortium Research Application in order to facilitate the conduct of basic science research in TS.
4. That the American Tuberous Sclerosis Association (ATSA), when appropriate, be an active participant of any effort(s) initiated by this Committee on behalf of Tuberous Sclerosis.

tuberous sclerosis association of america, inc.

TUBEROUS SCLEROSIS SCIENTIFIC ADVISORY BOARD

Richard J. Allen, M.D.
Prof. of Pediatrics & Neurology
Univ. of Michigan Medical Center
Ann Arbor, MI

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Roger Williams General Hospital
Providence, R.I.

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Tufts Univ School of Medicine
New England Medical Center
Boston, Mass.

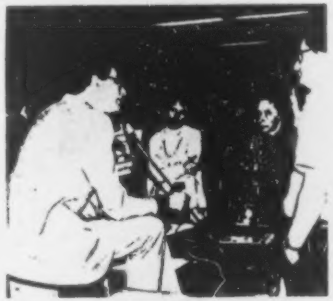
AMERICAN
TUBEROUS
SCLEROSIS
ASSOCIATION

A.T.S.A.

A National Health Agency For The Combined Federal Campaign

A.T.S.A. PURPOSES AND GOALS

I. RESEARCH
II. PUBLIC AND PHYSICIAN EDUCATION AND AWARENESS
III. CASE FINDING
IV. EARLIEST IDENTIFICATION
V. TO HELP VICTIMS AND THEIR FAMILIES



A.T.S.A. is a non-profit tax exempt organization of patients, parents, physicians and friends, who serve . . . .
Because . . . . we care!!!

Tuberous Sclerosis (T.S.) victims may have many physical handicaps and learning disabilities.

AMERICAN
TUBEROUS
SCLEROSIS
ASSOCIATION

A.T.S.A.

- Needs your help!!
  Too little is known about T.S.
- Research is vitally needed to find methods of prevention and treatment for T.S.
- Membership is open to anyone interested in helping to further the goals of A.T.S.A.

For further information, write or call:

A.T.S.A.
P.O. BOX 44
ROCKLAND, MA 02370
NATIONAL HEADQUARTERS
TELEPHONE 617-878-5528
TOLL FREE: 1-800-446-1211

A National Health Agency For The Combined Federal Campaign

A.T.S.A.

AMERICAN TUBEROUS SCLEROSIS ASSOCIATION

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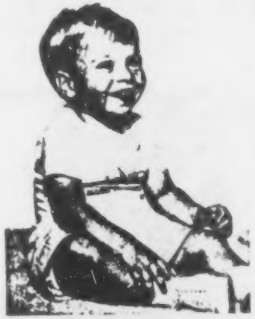

Tuberous Sclerosis (T.S.) may vary from very mild to extremely severe. A mildly affected person may be entirely normal mentally and physically.

Tuberous Sclerosis (T.S.) in its severe form can be very devastating, making the victim completely helpless and dependent.

WHAT IS TUBEROUS SCLEROSIS?

Tuberous Sclerosis (T.S.) is a genetic disease; individuals afflicted with the disorder are born with it. T.S. is generally characterized by one or more of the following conditions:

I. EPILEPSY
II. MENTAL RETAPDATION
III. TUMORS
IV. PHYSICAL HANDICAPS
V. HYPERACTIVITY AND BEHAVIORAL PROBLEMS

A.T.S.A.

- T.S. has no known cause or cure.
- Drugs may be used to help in the control of seizures and hyperactivity.
- There is no medication to combat the disease.
- Doctors feel there are more undiagnosed cases than there are correctly diagnosed cases.
- The importance of diagnosis is that a mildly affected parent, who is not aware of having T.S., may give birth to a severely handicapped child.
- For more information write or phone national headquarters.

Tuberous Sclerosis (T.S.) victims may have many physical handicaps, learning disabilites, hyperactivity and behavioral problems.

Tuberous Sclerosis (T.S.) although little known to the general public, is one of the most common genetic diseases. T.S. affects both males and females and may occur in any race.

Mr. **Natcher**. Doctor, you have made an excellent statement. We appreciate your appearance before the committee. Where were you born, Doctor?

Dr. **Lavenstein**. Baltimore.

Mr. **Natcher**. Thank you very much, you have given us a good statement.

Monday, May 5, 1986.

FOGARTY INTERNATIONAL CENTER

WITNESS

DR. HAMILTON WEBB, VICE CHAIRMAN, BOARD OF DIRECTORS, GORGAS MEMORIAL INSTITUTE

Mr. **Natcher**. Dr. Webb, it is a pleasure to have you before the committee again.

Dr. **Webb**. I am Dr. Hamilton B. Webb, Vice Chairman of the Board of Directors, Gorgas Memorial Institute. Dr. Jacobs, the Chairman, who submitted the written testimony before you, is under medical care and has asked that I represent him on this occasion.

I request that his written statement be included in the record.

The Gorgas Memorial Institute found it necessary to close the building, No. 265 in Ancon, that formerly housed the Middle America Research Unit of the National Institute of Allergy and Infectious Diseases, in 1982, and to trim personnel.

This was done at an exceptional expense of about $500,000, which was borrowed from the Social Security Administration of the Republic of Panama. We are in the process of repaying this over a period of 10 years.

Our appropriation, which was $1,800,000 in 1981, has increased only slightly, but has now been reduced by the automatic cut mandated by the Gramm-Rudman-Hollings Act. We are still suffering the effects of severe fiscal straits.

We are surviving and doing good work, but we cannot tolerate more losses from our basic support. We are not able to improve the plant and to grow at a time when U.S. national and worldwide interest in the diseases of the tropics is increasing. The Cubans are recruiting in Panama students for their tropical medicine education and training programs.

There are things we should be doing at the Gorgas Memorial Library in Panama. We should be improving our library, which is considered the best between Mexico and Brazil, and is extensively used by students and health personnel in Panama.

We should be training more than a few Navy medical officers. We should be monitoring the environment more closely and for more diseases and potential plagues than just yellow fever. Yellow fever sweeps across Panama, and has come into the United States in the past. We keep a continuous monitor on it and stop it at the Canal frequently.

AIDS began as a tropical disease, but escaped Africa when no one was watching. We think that there is a good deal more monitoring of diseases to keep them from getting out of hand.

Presently, we are running as far as we can just to stay in place, and are not quite maintaining that. If we can reestablish fiscal stability, we may be able to attract donations and contracts which will enable us to fulfill the scientific and educational responsibilities which we feel bear upon us.

Thank you. We are very grateful for the contribution the Congress has made to us for the last 15 years, and we will endeavor to use it to our best abilities, and the best purposes that we can, and we thank you very much.

Mr. NATCHER. Thank you very much, Dr. Webb. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Dr. Jacobs follows:]

Hamilton B. Webb, M.D.
552 Lake of the Woods
Locust Grove, Virginia 22508

CURRICULUM VITAE

School:	Phillips Exeter Academy		1931
College:	Yale University, BS		1935
	Columbia University, MD		1939
Internship:	Bellevue Hospital, New York City (Chest Disease Service)		1939
	Lenox Hill Hospital, New York City (Rotating)		1940
Residency:	Lenox Hill Hospital, New York City (Medicine & Chest)		1941
Post-Doctoral:	New York University School of Medicine (Department of Therapeutics)		1942
	USAF School of Aviation Medicine	1944 &	1955
	USN School of Preventive Medicine		1954
Certification:	American Board of Preventive Medicine		1955
	AMA Physicians Recognition Award	1971 &	1975
Practice:	Internal Medicine (Cardiology)	1941 -	1944
	General Medicine, Cheyenne, Wyoming	1945 -	1948
	Aviation Medicine	1944 -	1972
	Preventive Medicine	1973 -	-
Appointments:	Lecturer in Aerospace Medicine University of Kansas Medical School	1963 -	1964
	Lecturer in Preventive Medicine George Washington Univ. Medical School	1973 -	1978
	Vice President, Gorgas Memorial Institute	1976 - 1983 -	1979 1984
	Vice Chairman, Gorgas Memorial Institute	1984 -	present
	President, Council of Federal Medical Directors		1977
	Library of Congress, Chief of Health Services	1973 -	1977
	Medical Director, King Khalid City Construction Project, Saudi Arabia	1979 -	1980

STATEMENT BY

DR. LEON JACOBS
CHAIRMAN, BOARD OF DIRECTORS
GORGAS MEMORIAL INSTITUTE OF TROPICAL
AND PREVENTIVE MEDICINE, INCORPORATED

BEFORE THE

HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES

AND EDUCATION APPROPRIATIONS

99TH CONGRESS, SECOND SESSION

23 April 1986

Name of Organization: GORGAS MEMORIAL INSTITUTE OF TROPICAL AND PREVENTIVE MEDICINE, INCORPORATED

Name and Title of Witness: DR. LEON JACOBS
CHAIRMAN, BOARD OF DIRECTORS

Date and Time: WEDNESDAY, APRIL 23, 1986
10:35 A.M.

Mr. Chairman and members of the Subcommittee:

I wish to thank you for the opportunity to make this presentation.

I am Leon Jacobs, Chairman of the Board of Directors of the Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated (GMI). My curriculum vitae is attached to my written statement.

Three years ago I came before this Subcommittee to request reinstatement, in the appropriation of the Fogarty International Center of the National Institutes of Health, of the annual contribution to the Gorgas Memorial Institute which had been deleted from the administration request for fiscal year 1984. The Congress has, since 1928, provided an annual contribution to GMI for the operation of the Gorgas Memorial Laboratory (GML) in Panama. This contribution has been channeled, administratively, through the Fogarty International Center, since 1971. Prior to that year, the National Institute of Allergy and Infectious Diseases was the agency administering the contribution, and before that arrangement was made in 1958, the Department of State passed the funds to GMI.

Because GMI was classified by NIH as a "center", and because NIH was planning to delete support for some centers in its modified appropriation request in the Spring of 1983, the request for funds for GMI was removed from the altered request for the Fogarty International Center. In letters to you and to Senator Weicker and his colleagues in the Senate Subcommittee, and then in statements I made before your and his committees, I pointed out that the Gorgas Memorial Institute and Laboratory would be dead unless funding was restored. You and your colleagues in the Senate rescued us, on the basis of reports prepared by the Office of Technology Assessment (OTA) and the General Accounting Office (GAO). Their reports recommended continued operation of GML and suggested that improvements be made in management and that GMI seek outside funds for enhanced support.

In 1984 and 1985, I was able to report to you that the Gorgas Memorial Laboratory was consolidating its operations and its facilities in Panama City and giving up the expensive Building 265 in the former Canal Zone. Personnel reductions had been accomplished and refurbishing of laboratories to bring all the units together was proceeding. Last year I could tell you that the GML had grants and contracts for about $1,000,000 for research and training. The major items among these projects are still in operation this year. These are epidemiological studies of human T-cell leukemia virus in Panama; epidemiology of cervical cancer in Panama, Colombia, Costa Rica and Mexico, for which GML is the prime contractor; malaria drug studies financed by the U. S. Army; and the tropical medicine course for U. S. Navy physicians. Most of the smaller projects mentioned in 1985 are also still being pursued.

I emphasized last year, also, that it is our job, as managers of a small research enterprise, to make certain that we utilize our basic core funding to allow work to proceed on meritorious projects that are not receiving outside funds because of the vicissitudes of the funding systems or because it is necessary for us to maintain competence in areas of science that are not on the cutting edge of new concepts and technology but that are nevertheless important in monitoring disease spread and in providing basic data for new explorations. I pointed out that we had one project in arbovirology that we were supporting because we considered it valuable to continue even though it was in the category of "approved but unfunded" by NIH. This year, that project has been funded by NIH, and we are justified in having maintained it earlier. We are continuing to support modestly a project in acute respiratory disease. Our judgement of the value of this project has just been reinforced by a lead editorial in the January, 1986 issue of the American Journal of Tropical Medicine and Hygiene, entitled "Acute Respiratory

Infections are the Leading Cause of Death in Children in Developing Countries."

We have, in accordance with recommendations by OTA and GAO, expanded involvement of our Advisory Scientific Board (ASB) in scientific direction of GML. After an early August, 1986 site visit by specialists in epidemiology and virology, we held a full-day meeting of ASB members in late August to review both the report of that visit and of the parasitology site visit held in November, 1984. This was the first time that GMI has convened the ASB at its own expense for an entire day of discussion. The minutes of that meeting were submitted to the Congress as appendix D in the last Annual Report of the Gorgas Memorial Institute provided on April 1st.

You have already been informed of the general agreement GMI has with the University of Alabama at Birmingham. In efforts to develop specific collaborative projects, the new President of the Gorgas Memorial Institute and I traveled to Birmingham in January to explore areas of possible mutual interest, in discussions with the scientists in the School of Medicine and the School of Public Health. A GML scientist is about to visit Birmingham to discuss one possible project.

In recent discussions with the Dean of the Faculty of Medicine of the University of Panama, Dr. Gaspar García de Paredes, we have agreed to cooperate with that institution in the development of their new School of Public Health, to the extent of providing some of their students with laboratory and/or field experience in their fulfillment of the requirements for a Master's Degree in Public Health. It is my understanding that the creation of a School of Public Health has been a desideratum of many professional individuals in Panama concerned with preventive medicine. I have also been told by Dr. García de Paredes that the Cuban Institute of Tropical Medicine has been advertising for students from Panama. GML will welcome the new students to the extent that we are able to do so. We expect that it will be to our mutual advantage.

I have already mentioned that GMI has a new President. In accordance with changes in our by-laws enacted in 1984, on the basis of the recommendations in the OTA and GAO reports, GMI has separated the offices of President and Chairman of the Board. The President is a paid, full-time officer of the Institute; the Chairmanship remains a pro-bono, unpaid position. The President is with me today. He is James H. Marchbank. He is charged with improving the management of both the Institute and the Laboratory, and of developing fund-raising materials and prospects. In the latter enterprise, the Chairman and other members of the Board of Directors expect to participate.

However, the prospects of fund-raising are still nebulous. Our fund-raising consultants advised on our applying for support for individual projects. On that score we do relatively well, as I pointed out last year. What we need is funding for renovating and building more physical plant, for special equipment, and for endowments of chairs and fellowships. These are large sums and we will have to work very hard to get them. Our President will have to demonstrate that we are a well-run enterprise, and that we merit contributions for growth and further development - not merely for staying alive.

For staying alive, Mr. Chairman, we must still rely on the Congress of the United States. A remote institution such as the Gorgas Memorial Laboratory, requires a core of support on which it can depend, and then it can seek individual project support, which we have been able to do in the last few years. We are grateful for the wisdom of the Congress in maintaining us during recent very difficult times, and to the Government of Panama for the large loan which their Social Security Administration made to us in 1983, and for the direct annual financial contribution and special tax exemptions provided to GML.

Just when the GMI/GML have the possibility of achieving stability and of growing, we are now confronted with cuts in basic support. We have already been informed that we will lose $86,000 from our F.Y. 1986 funds because of the automatic rescission called for in the recently enacted deficit-reduction legislation. If further cuts are demanded, we will be back again at the brink of disaster. We had already dissected the fat - and unfortunately some flesh as well - out of our organization before the $86,000 rescission. Further cuts, if they occur, will take only flesh and will be disastrous to the continued operation of an important outpost of the U. S. biomedical research and training enterprise. We request restoration of the entire original appropriation for F.Y. 1987.

Thank you very much.

CURRICULUM VITAE

Name: Leon Jacobs

Address and Telephone Number:

Home: 3705 Morrison Street, N.W.
Washington, D.C. 20015

Phone: 202/966-2674

Date and Place of Birth:

March 26, 1915
Brooklyn, New York

Educational Background:

Boys High School Brooklyn, New York		1927-1931
Brooklyn College Brooklyn, New York	B.A.	1931-1935
George Washington University Washington, D.C.	M.A.	1936-1938
George Washington University Washington, D.C.	Ph.D.	1939-1943 1946-1947
Tissue Culture Course, Mary Imogene Bassett Hospital, Cooperstown, New York		7/49-9/49
Course in Virology, U.S. Department of Agriculture Graduate School, Washington, D.C.		1949
Course in Ophthalmic Pathology, Armed Forces Institute of Pathology, Washington, D.C.		2/9-13/53
Course in Pathology, U.S. Department of Agriculture Graduate School, Washington, D.C.		1953
Course in Veterinary Pathology, Armed Forces Institute of Pathology, Washington, D.C.		1959

Professional Experience:

Junior Nematologist to Protozoologist, Division of Zoology, NIH	1937-1943

United States Army	1943-1946
Protozoologist to Scientist Director, NIAID, NIH	1946-1956
Head, Section of Protozoal Diseases, Laboratory of Tropical Diseases, NIAID, NIH	1956-1959
Chief, Laboratory of Parasitic Diseases, NIAID, NIH	1959-1964
Acting Scientific Director, NIAID, NIH	1964-1965
Scientific Director, DBS, NIH	1966-1967
Deputy Assistant Secretary for Science, DHEW	1967-1969
Assistant Director for Collaborative Research, NIH	1969-1972
Associate Director for Collaborative Research, NIH	1972-1978
Director, Fogarty International Center, NIH	1978-1979
Visiting Prof. of Microbiology, University of Arizona Medical School	1979-1981
Visiting Prof. of Microbiology, University of So. Florida Medical School	1980-1982
Scientific Director, National Society for Medical Research, Washington, D.C.	1981-1982
Scientific Consultant, National Society for Medical Research, Washington, D.C.	1983-

Membership in Scientific Societies:

American Society of Tropical Medicine and Hygiene	
Editor, Tropical Medicine News	1952-1955
Representative to National Research Council	1957-1961
Council	1964-1968
Vice President	1970
American Society of Parasitologists	
Editor, Journal of Parasitology	1955-1958
Chairman, Committee on Business Operations	1959-1960
Council	1963-1966
President	1978
American Association of Immunologists	1956-1980
Helminthological Society of Washington, President	1950
Tropical Medicine Society of Washington, President	1971-
Society of Protozoologists	1955-1980

American Association for the Advancement of Science

Sigma Xi

New York Academy of Sciences

Research Interests:

Cultivation, epidemiology, and pathogenicity of parasitic protozoa; immunology and serology of protozoan and helminthic infections. Particularly interested in toxoplasmosis (life cycle and epidemiology, immunity, diagnostic procedures, ocular and other clinical manifestations and serology.)

Professional Publications:

Bibliography attached.

Other Activities:

Lectures at Johns Hopkins University School of Hygiene and Public Health	1956-present
Lectures at Georgetown University Medical School	1965-1968
Lectures and laboratory teaching of parasitology at Western Reserve University Medical School	1954-1958
Representative of the American Society of Tropical Medicine and Hygiene to the National Research Council	1957-1961
Consultant, Committee on Uveitis, American Academy of Ophthalmology and Otolaryngology	1957-1958
Chairman, Committee on Cooperative Publication, Conference of Biological Editors	1958-1960
Director and member of Executive Committee, Gorgas Memorial Institute	1969-1979
Chairman, Toxoplasmosis Sessions, 7th International Congresses on Tropical Medicine and Malaria	1963
Member, Executive Committee, Commissioned Officers Association of the U.S. Public Health Service	6/65

Member, WHO Expert Panel on Parasitic Diseases	
Chairman, Panel on Parasitic Diseases, U.S.-Japan Cooperative Medical Science Program	1965-1970
Member, Microbiology Subcommittee, Safe Drinking Water Committee, National Academy of Sciences	1976-1977
Chairman, Subcommittee on Research, U.S-Egypt Joint Health Working Group	1977-1979
Member, Board of Directors, Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated	1969-
President and Chairman of the Board, Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated	1983-
Adjunct Professor of Preventive Medicine, USUHS	1985-

Honors and Awards:

Army Commendation Ribbon	1945
Past President, Helminthological Society of Washington	
Biological Sciences Award of the Washington Academy of Sciences	1954
Arthur S. Flemming Award of the Junior Chamber of Commerce	1954
Brooklyn College Distinguished Alumnus Award	1955
Barnett Cohen Award, Maryland Society of Bacteriologists	1956
Fulbright Research Scholarship	1960-1961
Guggenheim Fellowship	1960-1961
Council, American Society of Parasitologists	1963-1966
Henry Baldwin Ward Medal of the American Society of Parasitologists	1963
George Washington University Alumni Achievement Award	1967
Distinguished Service Medal, USPHS	1966
Superior Service Award, DHEW	1968
Vice President, American Society of Tropical Medicine & Hygiene	1970
President, American Society of Parasitologists	1978

MONDAY, MAY 5, 1986.

FOGARTY INTERNATIONAL CENTER

WITNESS

THOMAS J. McANDREW, PROVIDENCE, RHODE ISLAND

Mr. NATCHER. Our next witness is Mr. Thomas J. McAndrew. Come on around, Mr. McAndrew, we are glad to have you before the committee.

Mr. McANDREW. I am here from Providence, Rhode Island, and I am here on behalf of the John E. Fogarty International Center for Advanced Study in the Health Sciences at the National Institutes of Health.

That institution came into being after my father-in-law, the late Congressman John E. Fogarty, died on the first day of the 90th Congress on January 10, 1967.

As you may know, he served in the Congress for 27 years, 16 of which he served as the Chairman of the Appropriations Labor, Health, Education and Welfare Committee. In that position, he had an opportunity to consider and pass upon many of the most important pieces of health care legislation, which are law today, to his lasting credit and that of the other distinguished Members of the Congress who have served and continue to serve our country.

Our country has become a model and the standard by which all other health care initiatives and practices are compared.

When Melvin Laird introduced the bill into the Congress to establish the John E. Fogarty International Center for Advanced Study in the Health Sciences, he did so out of the common belief that he and John shared that we live in an era when the attention of the world is focused on the efforts of nations to find ways to work together in common purposes.

In order to attain the highest level of health worldwide, international medical research must be promoted in the interests of scientific advances. We must support medical research performed by foreign scientists whenever such studies will advance both the health status of the United States and the country in which the research is conducted.

We must avail ourselves of the unequalled and often superior opportunities for our own research agendas. By uniting different approaches, greater progress can be made in a shorter amount of time. All mankind can benefit.

Recognizing that we are moving into an era of constrained resources, careful attention to priorities and the effective use of resources is paramount. We must assure that we do not retreat from our international prospective, involvement and leadership.

It is as important as ever, if not more so, that the United States and foreign scientists continue to have opportunities to meet, discuss and analyze their respective work; that U.S. and foreign scientists continue to have opportunities to collaborate in laboratories and share their unique talents toward common research objectives.

U.S. and foreign scientists must continue to examine together those major health research issues that evolve and emerge as common worldwide concerns. Certainly disease knows no social, economic or political barrier.

As the focus for the National Institutes of Health's international activities, the Fogarty International Center is unique in its responsibility to further international biomedical collaboration. It does at every level between scientists, institutions and governments.

Through its various programs that broaden international cooperation and agreement, the Fogarty International Center focuses to maintain U.S. leadership in biomedical research while taking advantage of opportunities offered throughout the world that will enhance the health of the American people.

Under its advanced studies program, the Fogarty International Center is continuing its activities dealing with those infectious diseases considered candidates for foreseeable eradication. For example, there are in the world an estimated 1,000,000 persons infected with yaws, a disease previously thought to be virtually conquered.

In certain regions, particularly in west and central Africa, the situation is precarious. The proportion of children with yaws is approaching that of pre-penicillin years.

In 1985, as a follow-up to its 1984 international symposium on yaws, the Fogarty International Center initiated a meeting in cooperation with the World Health Organization, held in Indonesia, of Asian countries to stimulate and strengthen primary health care services by coupling curative treatment with prevention, immunization.

As I understand it, future activities include a 1986 meeting on yaws to determine the present epidemiological situation in the African region and to consider integrated control measures in the cost of implementing yaws treatment in children as part of the primary health care services in each country.

The Fogarty International Center, together with a number of international organizations, is working to transfer state-of-the-art research results in the form of newly-developed diagnostic techniques.

The Institute is also taking advantage of research opportunities in this initiative to study penicillin resistance to the agent causing yaws. Such research is important because of penicillin resistance in the closely-related organisms that cause syphilis. It is further important to obtain this information to avert a potentially greater problem worldwide.

The Fogarty International Center International Research and Awards Programs sponsored foreign scientists to work in U.S. laboratories and sent U.S. researchers to foreign scientific institutions to conduct research of mutual interest, covering a wide range of scientific approaches.

Their research is concentrated in areas of every current global health concern, most generally metabolic and infectious diseases. Such programs not only contribute to the development of scientists and their country's resources, but more importantly, insure the continuation of American influence and leadership in biomedical science.

In its role as the operational link between the National Institutes of Health and other U.S. agencies and international organizations concerned with problems of world health, the Fogarty International Center facilitates the National Institutes of Health's collaborative relationships in biomedical research with over 70 countries.

Among these countries, China and India are of priority interest to the U.S. Government for maintaining strong cooperation in science and technology. With both countries, the NIH has major linkages of mutual benefit developed through the efforts of the Fogarty International Center.

One of the several activities with China which the Fogarty Institute facilitated is the development of an understanding with the Chinese Academy of Medical Sciences to implement a health scientist exchange program that is intended to foster contacts between scientists in areas outside those under the existing agreements.

In the instance of India, the Fogarty International Center is coordinating NIH requirements for funding under the new U.S.-India fund for cultural, educational and scientific cooperation.

This fund will support projects being proposed by NIAID, NHLBI, DRS, NIDR and NLM and thus U.S.-owned rupees will generate interest that can be used for U.S. projects.

The Fogarty International Center plays a key role in the technical management of a new major program with India: The vaccine action program which was announced by President Reagan and Prime Minister Ghandi following the Prime Minister's State Visit in June of 1985.

This new program follows other successful collaborations in science and technology but differs in that it is focused on disease and can be prevented through immunization programs, rather than on a particular component of technology.

It is comprehensive, covering a broad range of activities from basic research and development of new and improved vaccines to strengthen the quality control and vaccine manufacturing capability in the Indian private sector.

The vaccine action program incorporates interest both in science and technology collaboration and in immunization programs, the latter a critical feature of child survival programs throughout the country.

In addition, the vaccine action program will provide an opportunity for U.S. scientists who are working on vaccine development to pursue their studies through field study phase, an opportunity all too frequently unavailable.

In its role as the World Health Organization collaborating center for research and training in biomedicine, the Fogarty International Center sponsored, in cooperation with the Gorgas Memorial Library, the Pan American Health Organization and others, a workshop on training needs in entymology for vector bone disease research and control, held in Panama in October of 1985.

This project should be a significant factor in furthering regional and global strategies and manpower development for control of major vector bone diseases.

Further, in cooperation with the PAHO and the WHO, the Institute is currently conducting a project in the region of the Americas to identify patterns of international research collaboration between developed and developing countries.

As a result of this project, it is expected that the Institute will be able to recommend strategies for strengthening health research capabilities of scientists to participate in the research mission of the National Institutes of Health.

Of course, the Gorgas Memorial Institute and its laboratory in Panama receive cost support from the Fogarty International Center appropriation. The Fogarty International Center has supported of their research and is urging the Institute to develop additional sources of funding so that the laboratory may continue to be an important resource for the United States.

The Fogarty International Center also provides the Scholars-in-Residence Program which was established in 1969. Here, outstanding scientists and scholars are invited to the National Institutes of Health to collaborate with the scientific community and to contribute to the National Institutes of Health intellectual environment through research, seminars, lectures and conferences.

Scholars pursue individual studies of subjects of mutual interest to them and the NIH. Appointments are for up to 12 months, which can be taken in two terms over a three-year period.

This program offers scholars the unique opportunity to focus on research and writing scholars the unique opportunity to focus on research and writing that they might not otherwise be able to undertake.

As I understand it, to date, a total of 131 scientists have participated in the program. While most have come from Western Europe, North America, Japan and Australia, there are others who have participated from the Far East. In fiscal year 1985, 31 such scientists participated in the program 10 of whom were newcomers.

The collected bibliography now includes upwards of 500 titles since 1970, including over 60 monographs, numerous reviews of major topics and biomedical research in over 400 original articles in international referee journals.

During 1985 alone, 45 papers were published by scholars who participated in the program since 1983. For example, scholars publish papers on the development of vaccines against leprosy; the development of synthetic antigenens for preparation of hepatitis vaccines; the relationship between cellular oncogene expression and hematopoietic development; and a book summarizing knowledge about the characterization in synthesis of information-bearing peptides which include many hormones and nutra-transmitters.

John Fogarty believed in a representative democracy. He believed in the importance of Congress and he believed that one person could make a difference. I am confident, Mr. Chairman and members of this body, that you, too, believe in many of the same ideals espoused by Mr. Fogarty and are committed in the same manner to eradicate disease and health care problems that inflict oh, so many.

In this regard, I would ask your consideration to not only support the request submitted by the Administration on behalf of the Fogarty International Center but would ask you to consider supplementing that to enhance the Scholars-in-Residence Program as well as the International Research Fellowships that are provided through the Center.

While recognizing the economic constraints superimposed on the Congress and activities sponsored, when you weigh the relative merits of increasing activity in the biomedical research area, Scholars-in-Residence or International Research Fellowships or any other other worthwhile programs in the Fogarty International Center, I firmly believe, that they will somehow outweigh funding of other programs or activities that are reported to be wasteful and of no benefit to mankind.

In closing, I would like to thank you, Mr. Chairman, and other members of the committee, for having had this opportunity to come before you, for it has been a distinct pleasure.

Thank you.

Mr. NATCHER. Thank you very much, Mr. McAndrew. We appreciate your appearance before our committee. You have given us an excellent statement.

Mr. McANDREW. Mr. Chairman, may I inquire of Mr. Conte just one question?

Mr. NATCHER. Go right ahead.

Mr. McANDREW. How is the baseball team?

Mr. CONTE. Terrific. I think we have played something like 24 games, since I have been coach, and we have won them all but six.

Mr. NATCHER. That is a good record.

Mr. McANDREW. Very good.

Mr. NATCHER. Thank you very much.

MONDAY, MAY 5, 1986.

NATIONAL LIBRARY OF MEDICINE

WITNESS

NINA MATHESON, DIRECTOR, WELCH MEDICAL LIBRARY, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, REPRESENTING THE MEDICAL LIBRARY ASSOCIATION

Mr. NATCHER. Our next witness is Ms. Nina Matheson. Come around. We will be pleased to hear from you at this time.

Ms. MATHESON. Thank you, Mr. Chairman.

Mr. NATCHER. You have been before our committee before. We are glad to have you back.

Ms. MATHESON. Thank you, Mr. Chairman.

Mr. Chairman, Mr. Conte, I am Nina Matheson, the Director of the Welch Medical Library of the Johns Hopkins University Medical Institutions in Baltimore.

I greatly appreciate the opportunity to testify before you today in support of an adequate budget for the National Library of Medicine. I speak on behalf of the 5,000 members of the Medical Library Association, founded in 1898, and on behalf of the Association of Academic Health Sciences Library Directors, whose members manage the libraries of the medical schools accredited by the Association of American Medical Colleges.

The purpose of these two associations is the promotion of excellence in health through access to information for those in patient service, health education, and biomedical research.

We look to the National Library of Medicine for leadership to develop more effective ways to make knowledge available to advance U.S. science research, to improve our nation's health, and most importantly, given recent events, to safeguard our national health. With your permission I should like to depart from my testimony and spend my time on a few points.

Mr. Chairman, we recognize the national imperative reflected by the Deficit Reduction Act of 1986, but both Associations are convinced that the President's proposed fiscal year 1987 budget for the National Library of Medicine is not acceptable. We recommend a minimum appropriation level of $73 million, an increase of $16.5 million over the President's proposal, or $13.5 million over the current service level.

This support is critical both to maintaining the quality of health care and research in this country and to making a major breakthrough in knowledge management.

I think of our library system as analogous to the body's immune system. If we allow any part of the library system to weaken, we significantly lessen our ability to mobilize information in a timely fashion to attack and solve scientific and health care problems.

A great deal is at stake. As a result of brilliant scientific research, the knowledge base in science is growing at a rate that exceeds our capacity to manage it. How to record what we know and how to get to it when we need it and to use its power to our benefit are the major issues.

There is a disease model to illustrate the problem: Alzheimer's Disease. The horror of Alzheimer's Disease is action without mentation; disconnection of the store of knowledge from the decision making process. In a very real way that is what we face now and tomorrow if we do not take care.

Our stores of knowledge, our libraries, are not instrumented to channel that knowledge into informed decision making. Neither the hardware or the sophisticated applications programs are at hand. Furthermore, we lack the skilled researchers to design and develop systems.

The purpose of the National Library of Medicine's programs is to tackle these problems—to create those channels, to assemble the knowledge, to nurture new talent, and to direct the flow whereby the best information can be brought to bear when needed in real time decision making.

That is what their programs add up to. The Integrated Academic Information Management Systems, IAIMS program to link the medical literature with clinical information systems; the Unified Medical Language Program to create the foundations for future knowledge bases; the Medical Informatics Research Initiative to tackle fundamental and basic questions of knowledge management; Centers of Excellence to incubate a new generation of systems and talent; the Regional Medical Library Network to distribute information to practitioners wherever located; finally—and possibly most importantly, as we know you can't make hush puppies if you don't have seed corn somewhere along the way—maintaining and preserving the great collections of books and journals at the National Library of Medicine, which is the memory of biomedical science—all these form a coherent and interlocking program that can accomplish the aim of assuring informed, knowledgeable action.

We feel this is a critical time requiring strong support of the National Library of Medicine's programs. I have had the privilege of working for the two previous Directors of the National Library of Medicine, each of whom made a landmark contribution to science.

Dr. Frank Rogers developed MEDLARS, without which science cannot function today. Dr. Martin Cummings brought medical literature management into a scientific era with the research and development programs of the Lister Hill Center for Biomedical Communications, with the Regional Medical Library program, and with the third generation of MEDLARS.

Those were two exciting decades. I believe the next two promises even more important breakthroughs. We believe Dr. Donald Lindberg will take us into a new era—that of knowledge management. It is certainly a great technological feat to be able to put the contents of the Library of Congress on the micro chip. That, they tell us, will happen before too long.

But it is infinitely more important and difficult to represent the knowledge itself, the expertise, the analytic power of the brain, in useable form, on micro chips. This is the truly important work, the challenge, of the next decade.

We believe Dr. Lindberg has the vision. He has the skills to make that vision a reality. But he must have the resources to work with and he needs our moral, intellectual as well as financial support. We urge you to provide that support and to share our vision of the next generation National Library of Medicine.

Thank you.

Mr. NATCHER. Thank you very much. We appreciate your appearance before our committee. You have given us an excellent statement.

[The statement of Ms. Matheson follows:]

STATEMENT OF

NINA W. MATHESON

DIRECTOR OF THE WELCH MEDICAL LIBRARY

AND

ASSOCIATE PROFESSOR OF MEDICAL INFORMATION

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

BALTIMORE, MARYLAND

REPRESENTING THE MEDICAL LIBRARY ASSOCIATION

AND THE

ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARY DIRECTORS

AT OPEN HEARING

ON NATIONAL LIBRARY OF MEDICINE BUDGET

FOR FY 1987

5 MAY 1986

Mr. Chairman and Members of the Subcommittee:

I am Nina Matheson, Director of the Welch Medical Library and Associate Professor of Medical Information at Johns Hopkins University School of Medicine in Baltimore, Maryland. I am a member of the Medical Library Association, and served as its President for the 1983-84 Association Year, and a member of the Association of Academic Health Sciences Library Directors. I appreciate the opportunity to testify before you today on behalf of both organizations in support of an adequate budget for the National Library of Medicine.

The Medical Library Association, founded in 1898, has a membership of approximately 5,000 individuals and institutions, including libraries of academic health centers, hospitals, and industrial firms. The purpose of this professional organization is the promotion of excellence in health through access to information for those in patient service, education and research. The Association of Academic Health Sciences Library Directors represents those libraries whose parent institutions are the medical schools accredited by the Association of American Medical Colleges. Its purpose, as well, is to seek the widest and most efficient dissemination of health related information.

We are most appreciative of past efforts by this Subcommittee in preserving a program at the National Library of Medicine that can adequately support the health professions in maintaining and improving our nation's health.

We recognize the national imperative reflected by the Deficit Reduction Act of 1986, but both Associations are convinced that the President's proposed FY 1987 Budget for the National Library of Medicine is not acceptable relative to the role it has in safeguarding access to information by practitioners, researchers and educators. When such access is impaired, the nation is not well served.

Our recommendation, therefore, is for an appropriations level of $73,000,000. That is an increase of $16,500,000 over the President's proposal, or $13,500,000 over the current service level. Our primary concern is with the maintenance of the Library's basic operation, since the consequences of inadequate support would be felt in every part of the country. We would like to urge an increase of $3,000,000 for these basic services, i.e., an appropriation of $59,500,000.

Absent such support, the ensuing consequences are bound to be detrimental to the entire health community. The National Library of Medicine's role as the court of last resort for the availability of pertinent literature and as active disseminator of information would be severely compromised. While there will be no let up in the phenomenal increase in the biomedical literature, a growing percentage of this information would become inaccessible, either because the NLM could no longer acquire it, or because the processing, cataloging and indexing functions would be altered or delayed, and because the related MEDLARS system improvements could not be made.

A very recent letter received by a colleague of mine from a consulting physician at St. Luke's Regional Medical Center in Boise, Idaho, describes a life threatening situation with a 2-1/2-year old boy and how his life was saved when the hospital librarian conducted an immediate MEDLINE search of titles relating to therapy to be applied in this particular circumstance. Abstracts were printed for several of the more promising titles, and although many of the journals were not available in the St. Luke's Regional Medical Center Library, the abstracts contained much of the life-saving information. The letter, cosigned by the child's mother, concludes:

> Allen is now on the road to full recovery. Without the aid of the computer based search I would not have known how to proceed in the short time available for me to find an answer. We are indebted to the Pacific Northwest Regional Health Sciences Library Service and the National Library of Medicine for making available a data base that can help answer the tough questions. (Letter appended).

Closely related to the basic functions of making health information literature easily accessible, is the obligation to preserve the literature now held by the National Library of Medicine. This obligation was recognized by the Congress in the FY 1986 appropriations, but, in order to combat the rapid deterioration of valuable material, it is our recommendation to increase funds for this task by $600,000 for FY 1987.

The last component of NLM's intramural program we wish to call to your attention is that most important task of creating a Unified Medical Language system. This initiative deserves high priority, since the lack of a common vocabulary is a major impediment in constructing and implementing a system that will allow for easy communication, without hazardous translation, between and among researchers, practitioners, members of specialty societies, federal agencies, insurance companies, and academic staff. We believe that an appropriations level of $3,000,000 for FY 1987 is required to begin work on this project in any meaningful way.

We emphasize the success of the National Library of Medicine's Extramural Program, particularly the achievements made possible by the Medical Library Assistance Act. Among the most visible is the Regional Medical Library Program, whose biomedical communications network has created cost-efficient ways of disseminating information, training librarians, and encouraging the establishment of health related libraries. We recommend an increase for the Regional Medical Library Program of $500,000.

Another important area of the Medical Library Assistance Act is the grants program. Resource Improvement grants and Resource Project grants are frequently the sole means for advancing the application of information technology. Our recommendation is for an increase of $900,000 for this grants program, including additional funding for publication projects.

The Integrated Academic Information Management Systems (IAIMS) program is another NLM high priority initiative that is now ready for Phase III development. The purpose of IAIMS is to link the many related but unconnected files, records and databases of academic medical centers (including hospitals) into one configuration. The resulting sophisticated electronic communications system will allow clinicians, researchers, educators, students, and administrators rapid access to all information in a medical center. Phase I and II provided for planning and testing. For Phase III, the implementation phase, we recommend an increase of $3,000,000.

Thanks to NLM's vision and Congressional support, the Medical Informatics program has been nurtured for ten years. Drawing on expertise from a variety of fields, it is designed to develop computerized systems that allow interactive modes of communication between the computer and the clinician or scientist. We recommend that additional funding of $4,500,000 be provided, allowing NLM to give stable research support to investigators in the amount of $1,500,000, and with the remaining $3,000,000, to begin the establishment of Centers of Excellence in Medical Informatics at selected University campuses.

In order for the future of medical informatics investigation to be placed on a firmer foundation, training programs in informatics research must also be funded. Therefore, we recommend an increase of $1,000,000 for the Research Training in Medical Informatics program.

Thank you, Mr. Chairman.

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MONDAY, MAY 5, 1986.

NATIONAL LIBRARY OF MEDICINE

WITNESS

DR. MARSDEN S. BLOIS, PROFESSOR OF MEDICINE, SECTION ON MEDICAL INFORMATION SCIENCE, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Mr. NATCHER. Our next witness is Dr. Blois. We will be pleased to hear from you at this time.

Dr. BLOIS. Thank you very much, Mr. Chairman. I come before you as the President, Mr. Natcher, of the American College of Medical Informatics to testify about some of the problems and opportunities involved in managing medical information, and the relationship of this to the health of our citizens. In particularly, I wish to speak on behalf of the National Library of Medicine, the primary Federal agency, and a national focus of research and development in this field.

I am a Professor at the University of California Medical School in San Francisco, and I appreciate this opportunity to appear before you and present to you a recommendation of the College for a total National Library of Medicine appropriation of $72.9 million in fiscal year 1987, an increase of $13.5 million over the fiscal year 1987 current service level budget of $59.4 million, and please note, Mr. Chairman, these funds are spread across the totality of medicine in support of all diseases, all aspects of health care, and all the health professions.

While the general purposes of the medical library may be self evident, the meaning of the term "medical computing" and the activities encompassed by this new science of medical informatics is surely not. Medical informatics is not a household word yet.

This latter subject is concerned not with the organization, storage and distribution of books, but with the properties and processes of information itself. Information can be moved about far more rapidly, with more discrimination, and more inexpensively than can books, and entire technologies of computing and communicating are now available to support this activity.

Fortunately, these new capabilities are becoming available at a time when our medical and health systems are being overburdened with data and information. Health professionals spend an increasing proportion of their effort in information management: obtaining and recording patient data, interpreting laboratory and other diagnostic test results, planning diagnostic and treatment procedures, and keeping abreast of the medical literature. The potential offered to the health care system by this new science of medical informatics is very great. Let me explain why.

First, there is the role played by information itself in insuring high quality, effective and accessible medical care. Until recently, this has been the sole responsibility of scientific publishers and libraries. However, we are increasingly able to improve upon the conventional processes of information access and delivery by means of computer search and retrieval from bibliographic data bases combined with information delivery by electronic means.

The National Library of Medicine has already become the world leader through its creation and development of the MEDLINE/MEDLARS system.

Secondly, there is the question of the accessibility of health care. Here the critical step is the effective matching of human needs with fiscal resources. It requires particular kinds of data to determine the dimensions of our social and medical needs, the availability of suitable analytic methods for insuring that we are drawing the proper conclusions from the data, and the ability to successfully articulate these needs in order that proper remedies can be found.

The day-to-day managing of our health systems and resources requires that we have ready access to accurate and comprehensive data. This is a subject in which the Congress has had an enduring interest, and for good reason. It is no simple matter to discover what needs fixing, to understand what our health care costs really are, where further savings might be effected, and where unrecognized weaknesses still exist.

Thirdly, there is the process of medical research and its unique information requirements. Scientific communication requires the necessary network by means of which researchers identify problems and sharpen their perception of them, that discoveries are validated.

None of this happens by accident. It is important to appreciate what a small but essential fraction of the health research budget is needed to ensure that the results are converted into a practical and usable form.

On behalf of my colleagues already working on problems in these areas, I cannot overemphasize the importance of current and proposed research initiatives of the National Library of Medicine. Among these is the need for a unified medical language system. Such a system is essential if all participants in the health care system are to be able to refer to diseases, treatments and clinical events in an unambiguous and systematic way.

The need for this system becomes more urgent as computers are increasingly employed to manage the large masses of health related data. Failing such standardization, there seems little likelihood that physicians, health care planners, or government agencies will be able to obtain the comprehensive and accurate information they so badly need.

Encouraged by Congress, the National Library of Medicine has already initiated work on this significant project. To sustain this momentum, an increase over the President's 1987 budget request for the National Library of Medicine of $3 million will be necessary, and is fully warranted.

A second research initiative is its program for the integration of medical information systems. Known as the Integrated Academic Information Management System (IAIMS), this program was started two years ago. Its purpose is to support the development of techniques and policies that can serve to integrate the very different kinds of information obtained in the course of patient care, in medical research and in medical education.

A third proposed National Library of Medicine initiative has more general objectives than the preceding two and is supportive of both of them. This initiative is to develop a program of categorical support for the field of medical informatics itself. It is here where basic research and tool building most urgently needs to be done.

It is essential to discover much more about the properties of medical information and knowledge, how to represent them in computer programs and process them, and how to make data and information management more automatic so that human energy and judgment can be conserved and devoted to human problems.

The National Library of Medicine has encouraged the growth of this new scientific specialty which is now in a position to move on to a new generation of problems. Specifically, the College urges your support for an increase of 4.7 million dollars of the President's budget which will enable the National Library of Medicine to being a Centers of Excellence Program in medical informatics and to increase the support for investigator-intiated projects in this field.

Finally, the College supports an increase of 1.2 million dollars in the level of research training in medical informatics. This is an ongoing program of National Library of Medicine which has already been responsible for training most of the current corps of research workers in the field.

There is no more effective way for supporting these efforts than by insuring that highly qualified young professionals will be given the training which experience has shown to be necessary for their effective employment in this field.

Thank you again for the invitation to present this material to you. If you have any questions, I would be pleased to respond to them.

Mr. NATCHER. We want to thank you for your appearance before this committee. You have given us an excellent statement.

As I have said before, Doctor, we appreciate you ladies and gentlemen who travel long distances to come before our committee. You are from San Francisco. We appreciate your appearance.

You know, we hear all of the Department witnesses. We have three departments in this bill, the Department of Labor, the Department of Health and Human Services, and the Department of Education. We hear all these people and then we have our outside witnesses and I want you to know as one of the outside witnesses, we are concerned about what you have to say, Doctor.

We need all the help we can get on this committee. This is the second largest bill money-wise that we have on the Appropriations Committee, and Mr. Conte and I have believed for years, the most important one. We appreciate your appearance.

I just want you to know that and the same applies to all of these other ladies and gentlemen who have come long distances to talk to us about parts of this bill.

Dr. BLOIS. Thank you very much.

[The statement of Dr. Blois follows:]

Marsden. S. Blois, M.D.,

President, American College of Medical Informatics

Testimony Before the House Appropriations Committee:

Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies.

Monday, May 5, 1986 2:50 PM

Room 2358 Rayburn House Office Building

Statement by:

Marsden. S. Blois, M.D.,

President, American College of Medical Informatics

(Professor and Chairman,

Section on Medical Information Science,

University of California, San Francisco)

Testimony Before the House Appropriations Committee:

Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

Mr. Chairman and distinguished members:

I come before you as President of the American College of Medical Informatics to testify about some of the problems and opportunities involved in managing medical information, and the relationship of this to the health of our citizens. In particular, I wish to speak on behalf of the National Library of Medicine, the primary federal agency engaged in the support of this activity, and a national focus of research and development in this field.

I am a Professor at the University of California Medical School in San Francisco where I am engaged in teaching and research in Medical Information Science, and serve as the Director of the Medical Center's Melanoma Clinic. I appreciate this opportunity to appear before you and present to you a recommendation of the College for a total NLM appropriation of \$72.9 million in FY 1987, an increase of \$13.5 million over the FY 87 current service level budget of \$59.4 million.

While the general purposes of a medical library may be self evident, the meaning of the term "medical computing" and the activities encompassed by the new science of *medical infor-*

matics are not. This latter subject is concerned not with the organization, storage, and distribution of books, but with the properties and processes of information itself. Information can be moved about far more rapidly, with more discrimination, and more inexpensively than can books, and entire technologies of computing and communicating are now available to support this activity. Fortunately, these new capabilities are becoming available at a time when our medical and health systems are being overburdened with data and information. Health professionals spend an increasing proportion of their effort in information management: obtaining and recording patient data, interpreting laboratory and other diagnostic test results, planning diagnostic and treatment procedures, and keeping abreast of the medical literature. The potential offerred to the health care system by this new science of medical informatics is very great. Let me explain why.

First, there is the role played by information (scientific, clinical or management) in insuring high quality, effective, and accessible medical care. *High quality* care requires that health professionals remain familiar with the current state of medical knowledge, which in turn requires that they have continous access to accurate and timely medical information. Until recently, this has been the sole responsibility of scientific publishers and libraries. However, we are increasingly able to improve upon the conventional processes of information access and delivery by means of computer search and retrieval from bibliographic data bases combined with information delivery by electronic means. In this field, the National Library of Medicine has already become the world leader through its creation and development of the MEDLINE/MEDLARS bibliographic system. Conceived over 20 years ago, this remarkable system makes it possible for health practitioners, both urban and rural, to keep abreast of the enormous and growing medical and health related literature.

Effective health care entails a more complete understanding of both health and disease than we now have, if we are to advance both disease prevention and treatment. This understanding, slowly but systematically acquired through medical research at great cost and effort in laboratories, research clinics, and hospitals, is of little value until it is applied at the bedside. All of these processes are being strengthened by current developments in medical informatics.

Secondly, there is the question of the *accessibility* of health care. Here, the critical step is the effective matching of human needs with fiscal resources. It requires particular kinds of data to determine the dimensions of our social and medical needs, the availability of suitable analytic methods for insuring that we are drawing the proper conclusions from the data, and the ability to successfully articulate these needs in order that proper remedies can be found. In order to measure the effectiveness of our health programs, still other kinds of data must be collected, analysed, and evaluated.

The day to day [illegible] managing of our health systems and resources requires that we have ready access to accurate and comprehensive data. This is a subject in which the Congress has had an enduring interest, and for good reason. It is no simple matter to learn what needs fixing, to understand what our health care costs really are, where further savings might be effected, and where unrecognized weaknesses still exist. Sharpening these issues, obtaining the key data and acquiring a more accurate insight are information management problems. I will return to this point in a moment to comment upon what the National Library of Medicine and the medical informatics profession are doing to increase the sureness of the grasp we can exert on these management problems.

Thirdly, there is the process of medical research and its unique information requirements. Scientific communication (of which medical communication is a significant part) provides the necessary network by means of which researchers identify problems and sharpen their perception of them, that discoveries are validated, and from which finally emerges new understanding. None of this happens by accident. It is important to appreciate what a small fraction of the health research budget is needed to insure that the results are converted into a practical and usable form. That is, that research results are maintained in an organized manner and in a form in they which can be accessed and reviewed as needed in order to avoid attempts to re-discover facts already known, and to detect conflicting interpretations.

On behalf of my colleagues already working on problems in these areas, I cannot overemphasize the importance of current and proposed research initiatives of the National Library of Medicine. Among these is the need for a unified medical language system. Such a system is essential if all participants in the health care system are to be able to refer to diseases, treatments and clinical events in an unambiguous and systematic manner. The need for this system becomes more urgent as computers are increasingly employed to manage the large masses of health related data being generated. Failing such standardization, there seems little likelihood that physicians, health care planners, or government agencies will be able to obtain the comprehensive and accurate information they so badly need. Encouraged by Congress, the NLM has already initiated work on this significant project. The magnitude of the required effort will be great, comparable to the development of the original MEDLINE/MEDLARS system. To sustain this momentum, an increase over the President's 1987 budget request for the National Library of Medicine of three million dollars will be necessary, and is fully warranted.

A second research initiative of the NLM is its program for the integration of medical information systems. Known as the Integrated Academic Information Management System (IAIMS), this program was started two years ago. Its purpose is to support the development of techniques and policies, that can serve to integrate the very different kinds of medical information obtained in the course of patient care, in biomedical research, and in medical education. In this initiative, the information networking requires that data be integrated (1) at the level of its electronic processing, (2) at the institutional policy level ("who requires information and for what purposes?"), and (3) at the ethical and legal levels (rights of access and confidentiality). By broadly addressing the problem of information integration in this manner, we can expect to develop models of successful systems which can be adopted by the entire health care community.

A third proposed NLM initiative has more general objectives than the preceding two and is supportive of both of them. This initiative is to develop a program of categorical support for the field of medical informatics itself, to then provide a key to the other two objectives. It is here where basic research and tool building most urgently needs to be done, and where the Federal investment in medical informatics should prove most highly leveraged. It is essential to discover much more about the properties of medical information and knowledge, how to represent them in computer programs and process them, and how to make data and information management more automatic so that human energy and attention can be conserved and devoted to human problems. The National Library of Medicine has encouraged the growth of this new scientific specialty which is now in a position to move on to a new generation of problems. Specifically, the College urges your support for an increase of 4.7 million dollars over the President's budget which will enable the National Library of Medicine to begin a "Centers of Excellence Program" in medical informatics and to increase the support for investigator-initiated projects in this field.

Finally, I would urge your support for an increase of 1.2 million dollars in the level of research training in medical informatics. This is an on-going program of NLM which has already been responsible for training most of the current corps of research workers in the field. I should mention, however, that the number of trainees who are currently being supported by the National Library is 28. This is down from a total of 44 who were being supported as recently as 1980. This increase, which the College fully supports, will provide training for an additional 30 trainees, thus doubling the current level of research training support and restoring some balance between the proliferation of information, and its management and control. There is no more effective way for supporting these efforts than by insuring that highly qualified young professionals will be given the training which experience has shown to be necessary for their effective employment in this field. These trainees are typically young physicians, who are being trained as researchers in medical informatics and will be capable of carrying out these programs which I have described, in order to meet the future needs of medical care.

Thank you again for the invitation to present this material to you. If you have any questions, I would be pleased to respond to them.

MONDAY, MAY 5, 1986.

SUDDEN INFANT DEATH SYNDROME

WITNESS

DR. FRED MANDELL, BOARD MEMBER, NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION

Mr. NATCHER. Our next witness is Mr. Fred Mandell. We will be pleased to hear from you. Glad to have you, Doctor.

Where are you from?

Dr. MANDELL. Boston, Massachusetts. I am Fred Mandell. I am the Vice Chairman of the National Sudden Infant Death Syndrome Foundation, and I am a pediatrician at the Children's Hospital in Boston.

Mr. Chairman, not very long ago, a little baby was placed in a crib at night. The parents went in to check on that baby and the baby was not alive. These were very young parents. They had lots of "if onlys".

If I had only walked into the room, if I had only not left the child with a baby sitter, if I had only not changed the formula that day. They tended to magnify minor omissions. They felt guilty that they hadn't in some way protected this child.

Typically, the mother wanted to talk about it, the father did not. This family is probably typical of the thousands of families in this United States that have lost babies to the Sudden Infant Death Syndrome. Except this baby was Alex Garcia, the grandson of Congressman and Mrs. Robert Garcia. We know that Sudden Infant Death Syndrome is an enormous public health problem.

This year 7,000 babies will die of the Sudden Infant Death Syndrome. It is estimated that the worldwide figure is in excess of 250,000 babies. These are babies who are between one week and one year of age.

These are babies who die a very quiet death, usually in their sleep. Babies have died in car seats. Babies have died in mother's arms. We know now that these babies are subtly different. There is something different about them. Except as a pediatrician, I cannot pick them out. I can tell you that pediatricians all over this country desperately want to pick out these babies.

I can also tell you that research monies will not allow us to do this. We want to talk about the decade of the brain. Mr. Conte, one research program looking at the brains of those babies in its most intricate way costs $800,000.

Our total budget for research is just over $1 million. That leaves some two or $300,000 for all the other kinds of research. We cannot do it.

I also want to tell you that families again all over this country are suffering the excruciating guilt because of program curtailment, because of unavailable services and they continue to ask the question why did my baby die. I am here because the Sudden Infant Death Syndrome Foundation cannot pick up the pieces of 7,000 families. I am here because Alex Garcia is not.

Thank you, Mr. Chairman.

Mr. **Natcher**. Doctor, thank you very much. You have given us a good statement and we appreciate your appearance.

[The statement of Dr. Mandell follows:]

. . . in the belief that every child should live

National Sudden Infant Death Syndrome Foundation
Two Metro Plaza · Suite 205 · 8240 Professional Place · Landover, MD 20785
Telephone (301) 459-3388

TESTIMONY OF

FREDERICK MANDELL, M.D.
ASSOCIATE CLINICAL PROFESSOR OF PEDIATRICS
HARVARD MEDICAL SCHOOL

VICE CHAIRMAN,
NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION

ON BEHALF OF

NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION
8240 PROFESSIONAL PLACE, SUITE 205
LANDOVER, MARYLAND 20785

CONCERNING

FUNDING FOR SUDDEN INFANT DEATH SYNDROME RESEARCH
AND SERVICES

ON

MAY 5, 1986 - 2:55 P.M.

. . . *in the belief that* *every child should live*

National Sudden Infant Death Syndrome Foundation

Two Metro Plaza • Suite 205 • 8240 Professional Place • Landover, MD 20785
Telephone (301) 459-3388 (800) 221-SIDS - Outside Maryland

FUNDING AND POLICY RECOMMENDATIONS FOR FISCAL YEAR 1987 SUDDEN INFANT DEATH SYNDROME RESEARCH AND SERVICES

A. National Institutes of Child Health and Human Development (NICHD): $377 Million. This is essentially a "stay even" request to allow promising research which addresses critical needs in infant mortality. When breakthroughs are on the horizon, fiscal cutbacks must be averted.

B. NICHD: Pregnancy and Perinatology Branch -- SIDS-Specific Research: $5 Million. This level of funding would allow the NICHD to fund the Meritorious Research Grant application received in response to a broad-based Request For Applications. To support broad spectrum of vital SIDS research efforts.

C. NICHD: Pregnancy and Perinatology Branch -- Total SIDS-Related Research: $23 Million. To continue support of the substantial research efforts being conducted in areas of high risk pregnancy and high risk infancy (includes the requested increase in SIDS-Specific research dollars).

D. MCH: Federal Mandate of MCH Block Grant Funding of State SIDS Programs:

1. To allow restoration, maintenance and/or continuation of SIDS services and education programs in each state.

2. To ensure uniform reporting of SIDS statistics, vital to evaluating all research and program efforts.

3. To maintain the SIDS Clearinghouse, for distribution of informational and educational materials.

In December of 1984, an infant boy was placed in his crib for a nap. His young parents were secure with their new baby. Their lives had taken on a new joy with their first son. An hour later, when he was to be awakened, he was dead.

These young people had never before experienced death in their lives. They now suffered the harshest kind of grief reaction -- blaming themselves, feeling guilty, not wanting to face this tragedy. These parents experienced grief similar to thousands of parents all over this country: where minor omissions become magnified; where each parent has so many "if onlies" -- if only I had walked into the room sooner, if only I had been more observant, if only...

The baby - Alex - was Congressman and Mrs. Robert Garcia's first grandchild. He died of Sudden Infant Death Syndrome -- SIDS.

In 1986, the United States international ranking in infant mortality is an alarming 15th place. SIDS is the leading cause of death in infants between 1 week and 1 year of age and second only to accidents as the cause of death of children up to the age of 15. During this year more infants will die of SIDS than will succumb to cystic fibrosis, childhood cancer, childhood heart disease, and child abuse combined.

Today with increased public awareness of SIDS, or Crib Death, many parents, many grandparents fear this tragedy which claims the lives of over 7,000 infants per year in this country alone. The estimated worldwide figure of SIDS cases in 1985 is 257,000. This serious public health problem has to be the concern of everyone, for SIDS does not respect race, income level, or age of parent. It can happen to any one. Among your colleagues, it has happened to the Garcias.

Senator Ernest Hollings lost a grandchild to SIDS; Congressman Manuel Lujan - a child - and there are others. The death of an infant is truly a community event, impacting not only the immediate family, but also relatives, friends, neighbors, colleagues, involved professional (such as clergy, police, physicians, funeral directors, emergency medical technicians) and the list goes on.

When the tragedy of SIDS is finally eliminated, it will positively benefit millions of Americans.

As you may know, SIDS has plagued the human race since biblical times but not until this mid-century has serious medical attention been focused on its causes and concerns. It was not until 1974 that the government became involved through the Federal SIDS Act, but in spite of efforts of the private and public sector, the statistics have not changed.

However, key research in the last decade has increased our knowledge about SIDS and points to important avenues for further study. For instance, we now know that SIDS babies are subtly different from normal even from before birth. They develop more slowly in utero and continue to develop and grow more slowly after birth, their hearts beat faster, their breathing is faster, and they are ill more often than matched control infants. These differences are so subtle that even the most astute physician cannot yet identify the potential victim. This is one avenue that demands our increased attention. We are closer than ever before to achieving this capability. Only with continued research can scientists develop the means to diagnose susceptible infants and move towards preventing SIDS.

We now know that the welfare of mothers is critical in diminishing the risk of SIDS. Teenage mothers are more vulnerable than women in their 20's and 30's and smoking mothers are at substantially increased risk. Low birth weight babies are at significantly increased risk of SIDS. The need for programs of prevention based upon improvement of maternal well being is paramount..

We now know that the brainstems of some SIDS victims are slightly scarred. The brainstem is the seat of control for breathing and heart action, and it is extremely important to determine whether this "scarring" represents a cause or effect of SIDS. A new Request For Grant Application on SIDS from the National Institutes of Child Health and Human Development (NICHD) encourages investigators to focus efforts on neural control of cardio-respiratory function, particularly at the brainstem level. This is a vitally important line of inquiry.

We now know that there is a small overlap between unexplained prolonged infantile apnea (episodes of not breathing) and SIDS. Major research is underway to explore this relationship.

What do we know in summary? Experts in the field agree that there is likely more than one cause of SIDS. It is reasonable to consider that SIDS may result from a failure not just of one organ system or another, but from a failure of the complex interplay of the regulatory systems required to maintain life. The developing brain with its specific centers is the area where control of life sustaining functions takes place. It is imperative to provide research dollars for a number of promising hypotheses -- to fund more than a single avenue of research in order to maximize our chances of successful outcomes. This is a critical time. Because of today's new, highly sophisticated technology, we can now anticipate research efforts that we could not even dream of a few short years ago. As just one example, researchers can now study not only newborn infants but also the developing fetus, and can evaluate brain function, heart rate and breathing patterns in normal and at-risk fetuses and infants. It is expensive research; it is long term; but it is essential. We must not lose momentum at this strategic time.

In FY 1985, $1.133 million was allocated for SIDS-specific research at NICHD. The budget for SIDS specific research in 1986 is $1.1 million, after recision. The President's Budget for FY, 1987, earmarks $1.1 million for SIDS-specific research. A single project in the area of brainstem research easily costs over $800,000 (close to this entire budgeted amount). The NICHD Request for Applications has stimulated the preparation of numerous, varied and exciting proposals. The money must be made available to allow funding of the best of these.

Research money for primary SIDS studies has not kept pace with the demands and opportunities in this field. Even considering today's trends, SIDS Research has taken a disproportionate share of the cuts. Although the 1985, 1986, and 1987 budgets show a slight increase over the appallingly small amount of $657,000 earmarked in FY 1984, we have a long way to go to even catch up with funding levels of the late 1970's and early 80's. It is imperative that the $1.1 million earmarked for 1987 be expanded to $5 million (which would bring us back to the 1979 level) to allow optimal and expanded research efforts in this vital area.

Until SIDS is eradicated, affected families remain its victims; needy of information, counseling and comfort. The private sector has responded well with its support system built primarily upon those very persons who most intensely feel the need for support. But the fact is that they are incapable of filling the gap created by the curtailment of programs due to Federal budget cuts in the 80's. Just as NICHD is responsible for funding basic research, MCH handles clinical research and sees that research findings are applied to programs at the state level.

You know that direct grants to states ended in FY 1982 and the formerly Federally mandated State SIDS projects no longer exist. The capabilities of those projects across this nation are now extremely varied, from those that competently serve their community to those that have been cut out completely, with the majority struggling somewhere in between. All of them deal with the frustration of uncertain funding and the threat of termination.

Enough programs and research have taken place in the last decade to document the toll of blame and guilt and the complexity of responses of the wider community which SIDS affects. It is paradoxical that in 1986 a Federal Publication on SIDS will be issued detailing the complexity of responses from these very same groups which now are beginning to feel the shock waves of lack of services. Sadly, while infant mortality is the focus of MCH funding for 1986, a major segment, SIDS, has its public services eroded, weakened or terminated.

For example: Hawaii's former $50,000 budget was changed to $20,000. However, last September 30th, the state listed SIDS as "low priority" and all state funding for the SIDS Program was dropped. Montana receives no funding from MCH sources, has no state SIDS Program and only a National SIDS Foundation chapter in Billings to serve the entire state. The state has no allowance for autopsies (the only way to identify a SIDS case accurately) and as recently as last fall, a couple whose child died of SIDS, was initially charged with murder and exonerated only after a full investigation. Without a state program, large geographical states with sparse populations, such as Montana and also Wyoming and Idaho, literally have no ongoing education for public health departments. Alaska's last major educational effort for their widespread health districts was a 1980 teleconference.

There is no NSIDSF Chapter in the state of Idaho; no funds for the seven health districts and no legislation for SIDS autopsies.

Washington State has a catch 22 where Children's Orthopedic Hospital, the site of the SIDS Project, is the Block Grant recipient and hospital personnel needs supercede the Project needs, causing a continual reorganization because of lack of assured continuity. Although there were 181 SIDS deaths in 1984, the 24 hour phone service for families was discontinued in an effort to live within the hospital budget.

Texas has federal projects only in Houston and Dallas which receive $20,000 and $50,000 respectively. While there is state money for autopsies, a Justice of the Peace may request an autopsy but is under no obligation to do so. The State Health Department provides information to the public and professionals "as requested." For example, from the instructor of nursing education in San Antonio comes the information that "only lip service is paid" to educating parents about the importance of autopsies as their metropolitan health district has little formal SIDS management service. According to state statistics in 1984, only 78% of reported SIDS deaths were autopsied. Based on the 2.0 SIDS per 1,000 live births, Texas would have had an estimated 598 SIDS cases but only 351 were reported. The ignorance that a large percentage of SIDS deaths are unproven murders persists among a number of medical personnel.

The Utah Project no longer has the social workers and nurse, leaving only one professional to administer the program. Their small remaining budget which cut back on travel, counseling and educational services was further diminished by the requirement that they transfer to the Medical Department $125 per SIDS death whenever a coroner performs an autopsy.

Florida, once an outstanding Project, now only has resources to gather statistics. Louisiana, with its project in New Orleans is so minimal it is only a "central register" for the SIDS deaths in that state.

New Mexico will face a cutback in budget between 6 and 10% and will be further impacted by state cuts in the Office of the Medical Investigator out of which office they operate.

And so the accounting of cutbacks is tallied. We are currently left without any guarantee that states will continue SIDS-related services. Consonant with the Federal priority of reducing Infant Mortality, I would hope that you see the possibility of Federally mandated MCH Block Grant Funding of State SIDS Programs. Furthermore, because of Confidentiality Legislation in many States, doors do remain closed to programs in the private sector. Without a comprehensive Federal program, there can be no uniform reporting of statistics.

To me, as a physician, a SIDS death is antithetical. The ending of my practice of medicine before I can begin. To a parent it is the theft of joy, hope and the future. And yet we ask so much of those in our organization. We want them to be counseled and to counsel. We want them to be intelligent about their issues, sensitive and helpful managers. We count on them to recruit and use volunteers, to educate the community, to deal with the media and raise money for their cause. Surely it is not asking too much that from you we can win sound public policies and count on you to be partners in this endeavor.

. . . in the belief that every child should live

National Sudden Infant Death Syndrome Foundation

NICHD APPROPRIATIONS FOR SIDS-SPECIFIC AND SIDS-RELATED RESEARCH

(MILLIONS)

	1979	1984	1985	1986	Sequestration 1986	Recision 1986	1987 President's Budget	NSIDSF Recommendation FY 1987
SIDS Specific	$ 4.9	$ .657	$ 1.133	$ 1.300	$ 1.150	$ 1.100	$ 1.100	$ 5.0
SIDS Related	6.2	16.527	17.911	18.300	17.750	17.700	17.800	18.0
TOTAL	$11.1	$17.184	$19.044	$19.600	$18.900	$18.800	$18.900	$23.0

MONDAY, MAY 5, 1986.

NIOSH AND CDC

WITNESSES

DR. JEFFREY S. LEE, PRESIDENT, ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY

BILL PHILLIPS

Mr. NATCHER. Our next witness is Dr. Jeffrey S. Lee.

Doctor, you have been with us before, and that gentleman with you knows just about as much about this bill as we do. Come on up Mr. Phillips and have a seat with us at the table.

Go right ahead, Doctor. We will be pleased to hear from you.

Dr. LEE. Thank you, Chairman Natcher, Mr. Conte.

I am here representing the Association of University Programs in Occupational Safety and Health. I am here to urge you to restore funding for the training of professionals in the field of occupational safety and health through the NIOSH CDC budget.

Training is a mandated responsibility of NIOSH. The Occupational Safety and Health Act states "conduct, directly or by grants or contracts, educational programs to provide an adequate supply of qualified personnel to carry out the purposes of the Act".

NIOSH currently supports 14 comprehensive and multi-disciplinary educational resource centers or ERCs which are regionally located throughout the country, as well as several project grantees to fulfill this mandated responsibility. The program has unquestionably been a success, but equally it is critically dependent on Federal support for survival.

Over two-thirds of the academic programs are supported through NIOSH training funding. Virtually all of the institutions offering residency programs in occupational medicine and all of the academic programs in occupational health nursing are affiliated with ERCs.

In my prepared statement I have presented a graph comparing the training programs. A marginal decrease in funding has already had a significant effect on the training programs throughout the country. Last year, the University of Arizona was unable to maintain a full multi-disciplinary program and lost the ERC funding, reducing the number of ERCs to 14.

Although all of us have been moderately successful in obtaining partial State or institutional funding and have otherwise broadened our funding bases, we are still heavily dependent upon Federal support. A survey of ERC directors indicates that if Federal support is not restored, the number of graduates will drop drastically almost immediately to only 18 percent of the total graduated in 1981, and only an estimated one-fifth of the graduate degree program would remain viable over the long run. Virtually all of the Occupational Medicine programs and graduate Occupational Health Nursing programs would disappear.

The need for occupational health and safety professionals is overwhelming. I remember when I first entered this field as a young engineer in 1967 with the U.S. Public Health Service, working for the organization that later became NIOSH.

In 1968 we conducted a major survey of a representative number of companies to try to define the extent of occupational health problems nationally. One statistic has stayed with me all of these years.

Employers were asked whether they were aware of any health hazards in their plant, even if controlled. Three-fourths answered that they did not feel a health hazard existed in their plant. Trained surveyors then conducted an industrial hygiene survey of the plants, and only one quarter of the plants did not have any employees at risk. I am confident that we have made significant progress in education employers since this time, but we unquestionably have a long way to go.

The latest statistics show a work-related death occurs every 47 minutes and a work-related injury occurs every 17 seconds. Annual workers compensation payments exceed $16 billion per year and this grossly underestimates the problem since less than five percent of even severely disabled workers receive compensation benefits.

The majority of occupational disease simply goes unrecognized and becomes a significant contributor to the nation's health care costs and to the cost of our public supported medical care systems. Consider that the NIOSH training budget is only five one-hundredths of a percent of the annual cost of Workmen's Compensation.

If our graduates prevent only one percent of lung cancer cases that occur annually, the savings would easily pay for this entire training program.

Finally, I would like to point out that the effect of NIOSH training funds on academic programs is multiplicative. At Utah, for example, our continuing education program receives approximately $60,000 from NIOSH which basically pays the salaries of our continuing education staff yet has a budget of over 200,000.

Without NIOSH training to support salaries, our program would disappear. Research is another area where the NIOSH funding could indirectly foster development which could be effectively multiplied.

Last year the ERC directors in collaboration with NIOSH directors and CDC developed a new research program which would capitalize on this potential. This additional funding would allow the development of new research capabilities within the ERCs to stimulate research funding for three other sources and would further train students in research skills.

Last year in restoring funding for the ERCs this committee noted, the committee recognizes the important interrelationship between successful training and innovative research programs in an academic setting.

Graduates of more intensive research based training programs will help provide new imaginative and cost effective solutions to occupational safety and health problems in the United States. Such an expansion of the mission of ERCs to include research and research training to accompany ongoing practitioner training would be an important initiative in strengthening these graduated programs.

It would also stimulate ERC training and research efforts in programs designed to safeguard worker and community health in the cleanup of hazardous waste sites and in other high risk occupational settings.

In summary, I would urge the committee to restore funding for NIOSH training.

In 1976, Congress envisioned a ERC program with 20 centers costing $20 million. I am urging funding be restored at this year's level only after Gramm-Rudman cuts of 8.4 million plus a minimum amount of 1.5 million to begin this research initiative for a total request of 9.9 million.

Thank you, Mr. Chairman.

Mr. NATCHER. Dr. Lee, we want to thank you for your appearance before the committee. You have given us a good statement and we are glad to have both of you gentlemen.

[The statement of Dr. Lee follows:]

Association of University Programs in Occupational Health & Safety

Marcus M. Key, M.D.
Past President, 1980-81

Raymond R Suskind, M.D.
Past President, 1981-82

Don B. Chaffin, Ph.D.
Past President, 1982-83

Morton Corn, Ph.D.
Past President, 1983-84

Robert C. Spear, Ph.D.
Past President, 1984-85

Jeffrey S. Lee, Ph.D.
President, 1985-86

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Prepared Statement of

Jeffrey S. Lee, MPH, Ph.D.

President
Association of University Programs
in Occupational Health and Safety

and

Director
Rocky Mountain Center
for Occupational and Environmental Health
University of Utah

before the

Subcommittee on Labor, Health, and Human Services
and Education Appropriations,
Committee on Appropriations
U.S. Senate

April 24, 1986

Chairman Weicker:

My name is Jeffrey Lee and I am the current president of the Association of University Programs in Occupational Safety and Health and the director of the NIOSH Educational Resource Center located at the University of Utah.

I appreciate the opportunity to speak to this committee on behalf of the academic programs in occupational safety and health. In the past four years, my counterparts at the University of Cincinnati, the University of Michigan, the Johns Hopkins University, and the University of California at Berkeley have met with you for the same reasons I am with you today: to point out the critical importance of federal support for professional training in the field of occupational safety and health.

As you are aware, the Occupational Safety and Health Act of 1970 specifically mandated the then Secretary of Health, Education and Welfare, through the National Institute for Occupational Safety and Health (NIOSH), to "conduct, directly or by grants or contracts, educational programs to provide an adequate supply of qualified personnel to carry out the purposes of the Act" (Section 21(a)). In 1976, Congress authorized NIOSH to create 20 multidisciplinary Educational Resource Centers (ERCs), regionally located at major universities throughout the country. Funding for each of these centers was envisioned to be at least $1.0 million per year, and by 1980 the funding level of $12.9 million allowed funding of 12 centers. The academic community enthusiastically responded to this need, and by 1980 over 100 different academic degree programs were in place, offering degrees in Occupational Medicine, Industrial Hygiene, Occupational Health Nursing, and Occupational Safety. The number of graduates almost quadrupled from 1976

(176) to 1980 (747). Even more dramatic was the increase of continuing education programs offered by the institutions to practicing professionals to upgrade their skills. In 1976, approximately 1,600 individuals attended such courses; by 1980 this number had increased to almost 10,000 attendees.

In 1981, the funding level was drastically cut from $12.9 million to $8.7 million and further cut in 1982 to $5.8 million. In 1984 and 1985, despite the attempts of the Administration to eliminate these programs from the budget, funding was partially restored by Congress to $8.7 million. In 1986, funding was further reduced by the Gramm-Rudman-Hollings Bill to $8.4 million, and, as you all know, the 1987 Administration's budget once again completely eliminates funding for NIOSH training.

Approximately two-thirds of all the academic programs in occupational safety and health are supported through NIOSH training funding (1). Virtually all of the institutions offering residency programs in Occupational Medicine and all of the academic programs in Occupational Health Nursing are affiliated with ERCs (1).

A marginal decrease in funding has already had a significant effect on the training programs throughout the country. Last year, the University of Arizona was unable to maintain a full multidisciplinary program and lost their ERC funding, reducing the number of ERCs to 14. Although all of us have been moderately successful in obtaining partial state or institutional funding and have otherwise broadened our funding bases, we are still heavily dependent upon federal support. A survey of ERC directors indicates that, if federal support is not restored, the number of graduates will drop drastically almost immediately to only 18% of the total graduated in 1981, and only an estimated one-fifth of the graduate degree program would remain viable over the long run. Virtually all of the Occupational Medicine programs and graduate Occupational Health Nursing programs would disappear.

The need for occupational health and safety professionals is overwhelming. I remember when I first entered this field as a young engineer in 1967 with the U.S. Public Health Service, working for the organization that later became NIOSH. In 1968 we conducted a major survey of a representative number of companies to try to define the extent of occupational health problems nationally (2). One statistic has stayed with me all of these years. Employers were asked whether they were aware of any health hazards in their plant, even if controlled. Three-fourths answered that they did not feel a health hazard existed in their plant. Trained surveyors then conducted an industrial hygiene survey of the plants, and only one quarter of the plants did not have any employees at risk. I am confident that we have made significant progress in educating employers since this time, but we unquestionably have a long way to go. The NIOSH Minerva Project designed to introduce occupational safety and health into graduate business programs, utilizing ERCs in part, will help in this effort.

In Utah, a state not known for its heavy industry, every year I randomly pick a few small industries and offer them a free study as a training experience for my students. I continue to be amazed at the universal lack of awareness on the part of employers of the number and seriousness of health hazards that are present in their places of employment.

Consider further that much of the occupational disease that is occurring in this country goes unrecognized. It is not unusual to have an occupational disease not become apparent until decades after exposure. Since such diseases may have other causes besides occupational exposure, the association is not recognized by the employee, the employer, or even the employee's physician. Undoubtedly, these cases compose a significant percentage of those on the public-supported health care systems. They significantly contribute to the cost of health care in this country, which is currently over 10% of the gross national product--almost $300 billion--a cost often borne by the general taxpayer. As Senator Orrin Hatch stated at the Senate hearings investigating the suspected excessive cancer due to chemical exposures at Hill Air Force Base in Utah, "If there is a villain in this controversy, it is ignorance; ignorance of the proper methods relating to the protection of the employee from harmful chemical exposures; ignorance of the scientific knowledge related to the effects of the worker exposure to chemical substances; and ignorance of the now accepted fact that occupational causes of disease and illness often go undetected and unrecognized for a long period of time." I'm asking you today to help us reduce that ignorance.

The challenges facing professionals in the field of Occupational Safety and Health are increasing, not decreasing. We are only beginning to touch such critical areas as effects of chemical exposures on reproductive capability and neurobehavior and the occupational health risks of hazardous wastes.

Two recently released OTA reports support these conclusions. The OTA report "Preventing Illness and Injury in the Workplace" endorses the graduate training being provided by the ERCs and points out that cutbacks in federal training have reduced the number of trained professionals (3). The

OTA report "Reproductive Health Hazards in the Workplace" states ". . . what is known about reproductive health hazards is far outweighed by what is unknown" (4).

Occupational disease and injury are preventable. A major element of the solution is to train professionals who can recognize, evaluate, and control occupational hazards and occupational disease. The beneficiaries are the general public, not only employers of these professionals.

Successes lie in the number of illnesses and injuries that are prevented; the number that occur are the failures. In 1983, the National Safety Council reported a work-related death occurs every 47 minutes and a work-related injury every 17 seconds, resulting in annual workers' compensation payments of $16 billion (5), and this underestimates the problem. A survey done by the Department of Labor revealed that only 5% of workers who are severely disabled from an occupational disease receive worker compensation benefits (6). If partially disabled workers were included, the percentage would probably fall to about 2%. Consider that the total 1986 NIOSH training budget is only five one-hundredths of a percent of the annual cost of workers' compensation. Last year, my colleague from the University of California at Berkeley, Dr. Robert Spear, pointed out to this committee as an example: if one of our graduates in safety and ergonomics were to prevent just two back injuries from occurring (costing an average of $6,000/case in compensation alone), he would have paid for his education. There are approximately 150,000 cases of lung cancer occurring annually in the U.S.; probably 5-10% of these are caused by occupational exposures. If we were successful in preventing only 1% (or 1,500) of these lung cancer cases per year, the savings in health care costs alone would easily pay for the entire NIOSH training program.

Graduate training does not exist in a vacuum in a university setting. It feeds on and indirectly supports research and community service. Last year, the ERCs, in collaboration with NIOSH and CDC, defined a new research initiative whereby the mandated training function of the ERCs would be expanded to foster the development and expansion of occupational health research and the development of research skills in our students. Currently, 45% of NIOSH research grants are lodged in ERC institutions. The cross-fertilization of research and training is apparent and has great potential. The House Appropriations Committee has likewise noted the importance of this research effort within ERCs. Last year's House report language on occupational safety and health (pp. 32-33 of HR 99-289) states as follows:

> The Committee recognizes the important inter-relationship between successful training and innovative research programs in an academic setting. Graduates of more intensive research-based training programs will help provide new, imaginative, and cost-effective solutions to occupational safety and health problems in the United States. Such an expansion of the mission of ERCs to include research and research training to accompany ongoing practitioner training would be an important initiative in strengthening these graduate educational programs. It would also stimulate ERC training and research efforts in programs designed to safeguard worker and community health in the cleanup of hazardous waste sites and in other high-risk occupational settings.

Although NIOSH and CDC supported this initiative, higher levels within the Administration rejected the plan and again recommended total elimination of the ERC program.

We recognize that we all must do more with less when our country is facing a massive deficit. In 1976, Congress envisioned an ERC program with 20 centers and a $20 million annual budget. We are now, 10 years later, requesting only the current funding level after Gramm-Rudman cuts of $8.4 million, plus a minimal amount of $1.5 million to begin the research initiative, strongly supported by the House Appropriations Committee in its last year's report. I, thus, respectfully urge you to support the restoration of a total $9.9 million to the NIOSH training programs budget.

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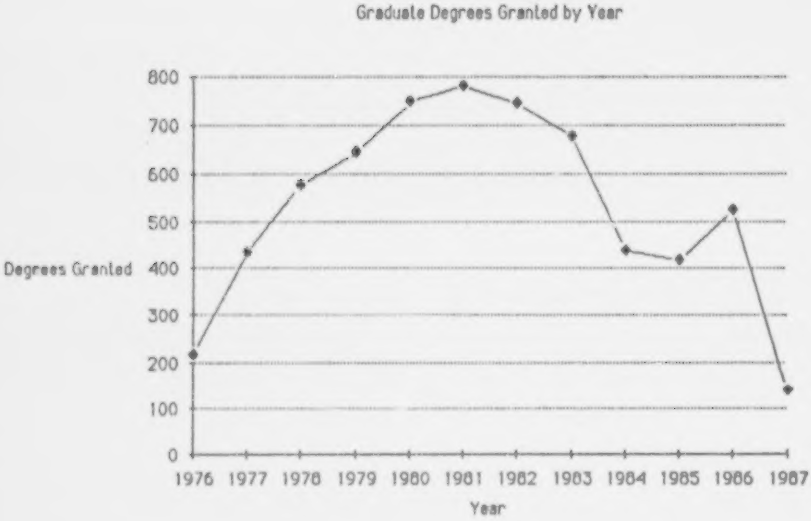
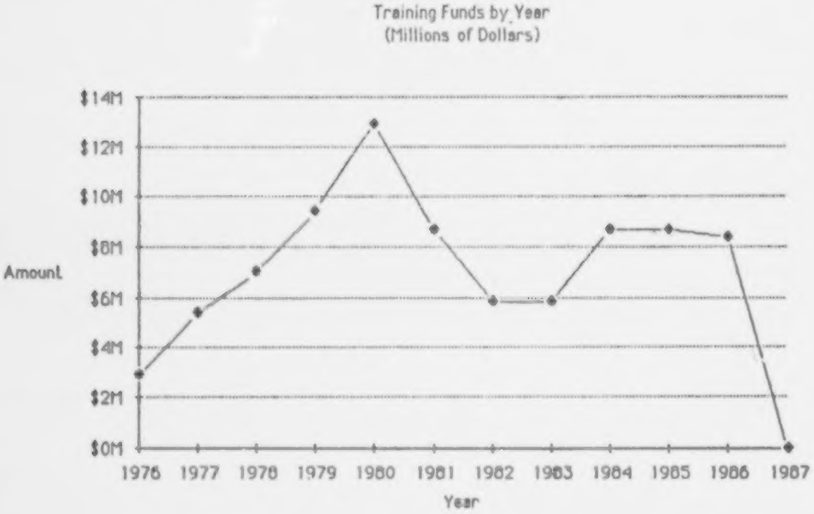
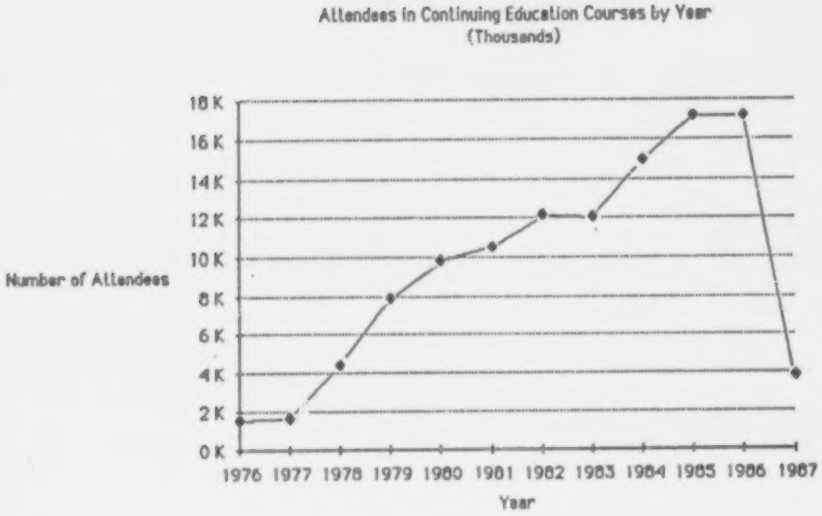




EFFECT OF FUNDING CHANGES ON NUMBER OF GRADUATES FROM BOTH ERC AND SINGLE-DISCIPLINE PROJECT GRANTS


Attendees in Continuing Education Courses by Year
(Thousands)
Number of Attendees
18 K
16 K
14 K
12 K
10 K
8 K
6 K
4 K
2 K
0 K
1976
1977
1978
1979
1980
1981
1982
1983
1984
1985
1986
1987
Year

MONDAY, MAY 5, 1986.

NINCDS

WITNESS

JOHN DONNELLY, NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. NATCHER. Our next witness is John Donnelly. We are glad to have you before the committee and this gentleman that is coming up here and sitting with you at the table knows just about as much or more than we do about this bill. We want to get you up here. Pleased to hear from you.

Mr. DONNELLY. A pleasure to be before you and this committee.

Mr. Conte and the Chairman have both been recipients of the Multiple Sclerosis Congressman of the Year Award.

Congressman Joe Early also on this committee is this year's recipient. It is not accident, because this committee has been in the forefront for biomedical research and we are very, very grateful, sir.

Mr. NATCHER. We all appreciate it, too.

Mr. DONNELLY. I am John Donnelly, Vice President for the National Multiple Sclerosis Society. I thank the committee for the opportunity to testify on behalf of our 500,000 members.

You have heard eloquent and informed testimony about the need for a well-balanced NIH program including grants, training, clinical trials and intramural research. You have heard also of the need to provide funds for construction and renovation and equipment and instrumentation to maintain our preeminent research infrastructure.

Rather than repeat these needs in detail, I would like to devote my allotted time to the economic argument for biomedical research.

As you know, we currently are spending a billion dollars a day on our health-care delivery system—around 11 percent of the GNP. That we spend heavily on health is not at issue. Whether we spend wisely is.

One of the biggest problems with our present health care system is that it focuses on treatment rather than prevention. Only three percent of the total health dollar outlay is earmarked for the scientist at the bench. Yet is basic research that provides the big payoffs.

The virtual elimination in this century of such dread diseases as polio, tuberculosis, diphtheria, smallpox and measles has saved the country untold billions. Polio immunization and vaccines for measles, mumps and rubella, for example, save us over two billion dollars a year.

Medical research offers an excellent return on taxpayer money. Studies show a $13 return for every dollar so invested by the Federal Government. Between 1900 and 1975 the benefits exceeded expenditures by $300 billion, adjusted for inflation.

There are, in addition, direct and indirect spinoffs. More than $40 billion is contributed annually to the GNP from medical discoveries used in non-health related products. And medical research has already spawned more than 100 new high-tech companies.

Polls show that an overwhelming majority of Americans believe that government funds for medical research should be increased by a sizable amount—even in this era of tight Federal budgets and soaring deficits.

Public support would be even stronger if more people realized the economic benefits of better health. To illustrate, consider the dollar value to the economy if scientists were to crack the mystery of Multiple Sclerosis by finding its cause and a cure.

According to a Wharton School of Business study, the lifetime costs of Multiple Sclerosis alone are at least $21 billion. That represents a combined cost of medical treatment and loss of income to the quarter of a million Americans with MS and their families.

Because Multiple Sclerosis is a "lifetime" disease—people rarely die from it—its economic consequences are much greater than for some of the so-called killer diseases. Solving the mystery of how this cruel crippler of young adults attacks the central nervous system would save the taxpayers billions in Medicare, Medicaid and SSDI payments.

It would also generate significant additional revenue for the Treasury by reducing dependence, putting the disabled back to work and contributing to the economy. The sick are tax consumers; the healthy are tax producers.

The billion dollars a day we now spend to care for the sick is the biggest single line item in the Federal budget. Bigger even than defense. We spend $2,000 a year per American for health care. By contrast the annual Federal investment in biomedical research is only $25 per person.

That doesn't make sense. Not when one major breakthrough could save billions a year—the first year and every year thereafter. For example, in 1982 alone, $7.7 billion was saved due to a reduced fatality rate for strokes.

Could money be spent more effectively? The needs in neurosciences are hardly overstated. The authority for this assertion is Congress itself. In late 1983 the Tracor-Jitco Report, a needs-survey commissioned by the Senate Appropriations Committee, recommended drastic increases for the study of neurological and communicative disorders, a disease group that affects 42 million Americans and costs the country $114 billion a year.

So many potential breakthroughs are now in sight that we should be steaming ahead at full speed on the biomedical research front. In fact, however, our laboratories are throttled down to one-third power.

For lack of funding, two of three NIH research applications judged highly meritorious by a rigorous peer review procedure are going unfunded. One scientist's success in obtaining a grant comes at the expense of other equally talented researchers. In this environment we live with the haunting knowledge that one of those unfunded researchers may have been the Dr. Jonas Salk of Multiple Sclerosis or some other maiming disease.

As a result of funding insufficiencies, many of our brightest young scientists and doctors are leaving government and academic research institutions for industry and private medical practice.

This flight will have serious long-term implications for basic research if allowed to continue.

There comes a time in history when opportunities must be seized or forever lost. We are at such a juncture in the biosciences. We no longer need to tolerate the existence of previously intractable diseases that kill and cripple us. The keys to solving many medical mysteries are almost at hand.

Progress now depends more on the degree of our commitment, the will of our people and the vision of our leaders—the Congress of the United States.

We realize your resources are limited, but we urge maximum funding for biomedical research and support the recommendations made to you by the ad hoc committee for biomedical research.

Thank you, Sir.

Mr. NATCHER. Thank you, Mr. Donnelly. Mr. Donnelly, I say this to you frankly on the record.

Terry Lierman, who sits there with you knows as much about this bill as anyone I know of. When he talks to you about the bill, we listen to him because he has the same interest that we have. I just wanted you to know that.

MONDAY, MAY 5, 1986.

REHABILITATION SERVICES

WITNESS

VERNON HAWKINS, ADMINISTRATOR, D.C. VOCATIONAL REHABILITATION SERVICES ADMINISTRATION REPRESENTING NATIONAL REHABILITATION ASSOCIATION AND COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

Mr. NATCHER. Our next witness is Mr. Vernon Hawkins. Glad to have you back.

Mr. HAWKINS. Mr. Chairman, I am pleased to be here today and offer testimony on behalf of the Council of State Administrators of Vocational Rehabilitation. The Council is comprised of all the chief administrators of the Public Rehabilitation Program.

We enjoy a common mission to achieve independence and self-sufficiency in order to enable them to participate in the mainstream of our society as citizens with equal rights, access and a minimum reliance of long-term on public sector support.

In that I am representing both the Council of State Administrators of Rehabilitation and the National Rehabilitation Association, I would like to officially submit for the record the written testimony of both organizations.

My oral comments will embrace the recommendations of both organizations. First, I would like to extend sincere appreciation to you and the committee for your consistent and enlightened willingness to invest public funds in the nation's rehabilition program.

Your past investments in these programs have returned significant dividends to our nation's taxpayers and more importantly to the persons with disabilities who receive rehabilitation services.

Few if any other programs funded by the Federal Government consistently return so many benefits, both financial and personal, to all segments of our society. This 65-year old program is the major resource for the State rehabilitation agencies as the primary provider of rehabilition services enabling persons with physical and mental disabilities to re-enter the work force and to obtain employment for the first time.

Implementation of the provisions of the Rehabilitation Act has resulted in individuals becoming independent in our public sector and in ensuring their independence and support by their families.

As a direct result, Mr. Chairman, the Vocational Rehabilitation Service's savings to the government accrues as competitive work generates increase tax revenue. It is my belief this serves most adults.

In order to accomplish that, Mr. Chairman, we must ensure there is adequate funding appropriated for this program. For we recommend very specifically that which has been identified in both the testimony submitted by the Council of State Administrators and support that also by the National Rehabilitation Association.

For those persons over the last past years you have contributed somewhere in the neighborhood of $1 billion and more to ensuring that persons with physical and mental disabilities find their rightful place in our society and we continue to commend you on that effort.

To carry out that program, we must ensure that there is an adequate staff, qualified staff to ensure the appropriations and they can carry out the task as specified in the regulation so we firmly urge the support of recommendations for training as indicated in both the Council of State Administrators' testimony as well as the National Rehabilitation Association.

To further support the effort of ensuring that persons move to independence, Mr. Chairman, we recommend and wholeheartedly support the support work concept as a new modality of services to provide individuals with the opportunity to move into our society in a much more competitive way than we historically have been able to provide services.

We believe and support as State public officials that this new supported work concept can act as an addendum to the service delivery system for person's who have disabilities. We further support the continuing of the independent living program as provided for in the legislation in parts A and B and recommend that the Congress support those fundings identified in parts A and B in the testimony submitted by the Council of State Administrators as well as the National Rehabilitation Association.

In closing, Mr. Chairman, as a State director and as a public servant providing services to persons with disabilities, I can say here in the District of Columbia it has been the primary resource that we have had available to provide services to persons with disabilities and that would enable them to move as to the bottom line into our society in a competitive way.

I thank you in closing for the opportunity to appear before you and urge your continued support as you historically have to ensure that persons with disabilities find a rightful place in our community.

We thank you for this opportunity.

Mr. **Natcher**. Mr. Hawkins, we want to thank you for your appearance before our committee. You, too, have made an excellent statement. We want you to know we appreciate it.

[The statement of Mr. Hawkins follows:]

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STATEMENT
OF THE

NATIONAL REHABILITATION ASSOCIATION

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION

RELATIVE TO FUNDING LEVELS FOR PROGRAMS
AUTHORIZED BY THE REHABILITATION ACT OF 1973, AS AMENDED

PRESENTED BY

VERNON HAWKINS

MAY 5, 1986

Mr. Chairman, members of the Subcommittee, I am here today representing the National Rehabilitation Association, an organization whose purpose is to promote and support rehabilitation for persons with disabilities.

I would like to extend the sincere appreciation of the approximately 17,000 members of the National Rehabilitation Association and its seven divisions - the Job Placement Division, the National Association of Rehabilitation Instructors, the National Association of Rehabilitation Secretaries, the National Rehabilitation Administration Association, the National Association for Independent Living, the National Rehabilitation Counseling Association, and the Vocational Evaluation and Work Adjustment Association - to you and this Committee for your consistent and enlightened willingness to invest public funds in the nation's rehabilitation programs. Your past investments in these rehabilitation programs have returned significant dividends to our nation's taxpayers, and more importantly, to the persons with disabilities who receive rehabilitation services. Few, if any other programs funded by the Federal government consistently return so many benefits, both financial and personal, to all segments of our society.

The National Rehabilitation Association's recommended levels for programs authorized in the Rehabilitation Act, as amended, are as follows:

BASIC STATE VOCATIONAL REHABILITATION SERVICES PROGRAM - SECTION 100 (B) (1). Mr. Chairman, our primary request is that the Appropriations Committee make available for the Basic State Vocational Rehabilitation Services Program for Fiscal Year 1987, $1,379.4 million. It is ironical that we are here today amid the great outcry to reduce federal expenditures and yet a program such as Vocational Rehabilitation, which breaks the dependency lifestyle for thousands of handicapped individuals, has not been recognized as a means to the end we all seek to achieve. We must recognize that it makes good common sense to expend our limited federal funds on programs that contribute to society's long-term stability rather than to expend these limited funds in give-away and benefits programs which are so often detrimental to the individual and to society. Our society needs to realize that disabled citizens do not need to be "paid off" with cash programs. They need, instead, services that can make them contributing members of society. We need to offer the opportunity for those services which will lead to independence and will make our disabled citizens taxpayers in order that they can contribute to the support of our government while, at the same time, provide them the opportunity to enjoy self-esteem.

This country cannot afford to disregard the tremendous labor potential that rehabilitated, disabled individuals can provide. We hear a great deal about the need for increasing productivity in the American work place. Let us not then reduce funding for a program such as Vocational Rehabilitation that can provide competitive workers who can help balance our budget in future years. Any federal policy to the contrary is not in the best interest of this country nor is it in the best interest of these citizens. Nor is it in keeping with what the taxpayers of our country have expressed that they want to see -- less costly and more efficient government. Simply put, Mr. Chairman, this unique state-federal program is not a burden upon our taxpayers but instead is an investment in our future. I would also remind you that Vocational Rehabilitation is not a new program, but is one that has been tried and proven for more than sixty years and is a successful program that can be pointed to with pride.

Mr. Chairman in order to get our house in order and our priorities straight, let me point out some interesting figures that demonstrate what I am trying to say. It is estimated that payments for dependent, disabled persons now account for one out of every thirteen dollars in the federal budget. Almost $40 billion in federal funds now goes for disability related benefits, for such expenditures as public assistance, medical support and other related payments. Obviously, this is an area in which dramatic and impressive cuts can be made, but only if we are willing to help disabled citizens become self sufficient and independent. That can be accomplished, but only if we first invest in Vocational Rehabilitation programs which can develop the potential of those disabled citizens. Put another way, we currently spend only about 2% on Vocational Rehabilitation programs of the amount we pay out in benefits. This pattern must be changed if we are to have a future we can afford. Not only is Vocational Rehabilitation a wise investment, it may be the only alternative we can afford.

The National Rehabilitation Association's recommendation is considered to be the amount needed to begin to restore the purchasing power of the Rehabilitation dollar to its 1979 level. Because of scarce resources, State Vocational Rehabilitation Agencies are only able to serve approximately one out of every twenty individuals who need services. Millions of eligible people who could be served, are not served. People with mental and physical disabilities comprise a significant portion of the Nation's population - an estimated 36 million individuals. According to recent data from the National Center for Health Statistics, approximately 22 million individuals are disabled in such a way as to chronically limit their ability to function. The size of the disabled population is not static, but continues to grow — through accidents, injuries, illness, and the occurence of individuals disabled at birth — at an estimated rate of 50,000 annually. It is estimated that 85,000 fewer persons will be served in FY 1987, if funds for the Vocational Rehabilitation State Grants Program are reduced in FY 1987, as the President proposes.

In addition to the humane arguments for funding, Department of Education data have shown that the total State-Federal investment in Rehabilitation for any given fiscal year is totally paid off in four-years, due to increased tax revenues and decreased dependency on government services.

REHABILITATION TRAINING. NRA recommends that rehabilitation training programs, a critical element in providing services to persons with disabilities, be funded at $32 million for FY 1987. The quality and success of any direct service program is directly related to quality training for service providers charged with turning rehabilitation goals into realities. We cannot allow documented shortages in many rehabilitation professions to continue without lowering the overall effectiveness and success of the nation's rehabilitation programs. In addition, the Rehabilitation Counselors on the job need to have their skills constantly need updated. The bottom line, Mr. Chairman, is the need for resources in order to employ truly qualified, well-trained personnel to serve disabled persons in order to facilitate their entry or re-entry into the mainstream of American life. If this is to happen, then we must provide adequate salaries to pay them, we must give additional tools and knowledge to the many excellent counselors who are already working for our State-Federal programs, and we must work to ensure that adequate funds are made available to accomplish this. In order to provide the highest quality of rehabilitation services for persons with disabilities it is imperative that Congress provide $32 million for this program.

COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING - TITLE VII NRA recommends an investment of $61.5 million for the Independent Living Rehabilitation Services Program, Parts A, B, & C. This important component of the Rehabilitation Act was added in 1978.

When the Congress orginally enacted Part A, in 1978, a funding level of $200 million was authorized, and was viewed as the minimum amount necessary to address the needs of individuals who have severe disabilities. That great unmet need still exists.

For the first time, in FY 1985, the Congress appropriated funds for this Program. The $5 million appropriated in FY 85, and the $11 million in FY 86, are viewed as seed monies to "assist the State VR Agencies to use funds...to establish a sound basis for future additional funding of this activity." (S. Rept. 98-544). These monies are being used by each State to enhance or establish a framework for the provision of services to persons with the most severe disabilities. Now is the time for the Congress to appropriate sufficient funds for the establishment of a truly nationwide service delivery system under Part A. The National Rehabilitation Association recommends $30.0 million be appropriated for Part A.

Part B funds 160 centers throughout the country. The National Rehabilitation Association urges $26 million be appropriated to fund the program which establishes and operates center programs essential to up to 40,000 individuals with severe disabilities. Funding at the FY 1987 level recommended by the NRA would allow the establishment of up to 15 new centers, at an average grant of $200,000. Moreover, new funding would permit the expansion of independent living center services specifically for individuals who have previously been underserved by this program, including people with mental retardation or mental illness.

Part C appropriations in the amount of $5.5 million are requested to initiate independent living services for older individuals who are blind. Without these services older persons who are blind are often in jeopardy of unnecessary nursing home placement at a public cost averaging $18,000 per year. As the elderly population increases, the need for these services will grow as well. By the year 2000, the number of people over age 75 will increase by 6 percent. Persons who become blind at a young age can be expected, for the most part, to share in this longevity and Part C type services are needed to cope with the emerging needs of this population.

REHABILITATION RESEARCH. The National Rehabilitation Association recommends appropriations of $49 million in rehabilitation research as administered by the National Institute for Handicapped Research. We are entering a new era in our nation, one that is exemplified by remarkable technogical advances. One area NRA especially wants to applaud are the efforts to encourage the development and delivery of rehabilitation engineering technology to the consumer. These scientific and technical achievements can, and should, be brought to bear in the problems faced by our nation's persons with disabilities. Funding for rehabilitation research will pay direct dividends in future years as we discover more effective ways of meeting the needs of persons with disabilities and incorporate technological and scientific advances in our direct rehabilitation services program. A $49 million budget will enable the needed growth in center programs, support 40 new research grants to individuals, comply with Congress's intent to increase funds for expanded support of existing centers and additional field initiated research grants, and allow NIHR to work with the National Institutes of Health in developing medical research training to be funded, which was funded in FY 1986. In addition, Congress has expressed concern that the NIHR has not given sufficient priority to people with mild and moderate head injuries and has accordingly directed NIHR to aggressively seek proposals which address this area.

SERVICE PROJECT

Client Assistance Program. This newly restructured program is in its second full year of operation. It is designed to advocate for the rights of VR clients and to work cooperatively with the State vocational rehabilitation agency. The National Rehabilitation Association recommends an appropriation of $7.5 million.

Projects With Industry. The successful placement of persons with disabilities as wage earners and taxpayers in the private sector is an essential part of rehabilitation. The National Rehabilitation Association recommends an appropriation in the amount of $18.0 million.

Other service projects that should receive full appropriations are:

Special Demonstration Project at $30.6 million.

Helen Keller National Center at $5.5 million.

Architectural and Transportation Barriers Compliance Board at $2.5 million.

Special Recreation Programs at $4.5 million.

EVALUATION. Section 14 of the Rehabilitation Act calls for the Secretary of the Department of Education to ascertain the impact of all programs authorized by the Act. The National Rehabilitation Association urges the Committee to restrict evaluation to only those programs authorized by the Congress. We urge the Congress not to let the Administration use these monies to test its new voucher experiment. The National Rehabilitation Association recommends an appropriation of $2 million.

INNOVATION AND EXPANSION GRANTS. The National Rehabilitation Association is excited about the restoration of funds for Innovation and Expansion Grants and that $9.0 million be appropriated in FY 1987 for this program. It is an appropriate and worthwhile Federal activity to encourage States to develop and implement innovative service delivery models. Through these modest efforts, the States can identify exemplary practices, and incorporate them throughout their entire services delivery system. A $9 million appropriation (half of the 1978 appropriation for this Program) would be an extremely wise investment.

CONCLUSION. The Rehabilitation Act of 1973, as amended, is one of the most complete well-written, and well-balanced pieces of legislation ever written. This program of Rehabilitation Services is a cornerstone in the governmental effort, at the Federal, state, and private sector levels, to assist Americans with disabilities in their efforts to achieve meaningful employment and self-sufficiency.

In one Act, provisions are included for a comprehensive, individually-tailored program of rehabilitation services to eligible physically and mentally disabled persons; a training program to fully prepare rehabilitation personnel; a research program to develop new techniques in providing services; a special projects program to target services to specific populations; a comprehensive services program for independent living for persons too severely disabled to benefit from traditional vocational rehabilitation services; and other specifically designed programs. The Rehabilitation Program signifies the Nation's recognition of its responsibility to provide disabled citizens with the opportunity to be a part of the mainstream of life as full participants.

The National Rehabilitation Association commends the U.S. Congress for its long history of progressive legislation and funding of rehabilitation programs. That Congress has responded positively to the rights and needs of persons with disabilities is at least in part because of its recognition that rehabilitation programs are a part of a stronger United States. We thank you and your colleagues in advance for appropriating funds for rehabilitation programs at the levels we have recommended in this testimony.

REHABILITATION ACT OF 1973, AS AMENDED
($ in millions)

Program	FY86 Appropriation	FY86 Post Sequestration	FY87 Authorization	Administration FY87 Budget	Coalition's Recommendation
Basic State Grant	$1,190.0	$1,145.0*	Pending	$1,100.0	$1,379.4
Evaluation (Sec. 14)	2.0	1.914	Pending	.6	2.0
Training	27.0	25.839	Pending	15.0	32.0
National Institute of Handicapped Research	44.0	42.108	Pending	39.0	49.0
Innovation & Expansion	9.0	8.613	Pending	9.0	9.0
Independent Living					
Comprehensive State Services, Part A	11.0	10.527	Pending	---	30.0
Centers for Indepen. Living, Part B	23.0	22.011	Pending	22.0	26.0
Services to Older Blind Individuals, Part C	5.0	4.785	Pending	---	5.5
Service Projects:					
Client Assistance	6.7	6.4119	Pending	6.3	7.5
Special Demonstration Projects	20.2	19.33	Pending	14.6	30.6
Projects with Industry	15.2	14.5464	Pending	13.0	18.0
Special Recreation Programs	2.2	2.1054	Pending	---	4.5
Helen Keller National Center	4.3	4.1151	Pending	4.2	5.5
Archit. and Trans. Barriers Compliance Board	1.97	1.89	Pending	1.97	2.5

*This represents the cost of living reduction for section 110.

TESTIMONY
# of the
COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

before the

HOUSE APPROPRIATIONS SUBCOMMITTEE
on
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES

on

Monday, May 5, 1986

Presented by:

Vernon E. Hawkins
Administrator
District of Columbia
Vocational Rehabilitation
Services Administration

COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The Council of State Administrators of Vocational Rehabilitation is an association comprised of all of the chief administrators of the public rehabilitation agencies providing services to persons with disabilities in the fifty states, the District of Columbia, and our Nation's territories.

These agencies constitute the state partners in the State-Federal Program of Rehabilitation Services for persons with mental and/or physical disabilities, as authorized by the Rehabilitation Act of 1973, P.L. 93-112, as amended. This 65-year-old program is the major resource for, and the State Rehabilitation Agencies are the primary providers of, rehabilitation services to our Nation's citizens with disabilities.

The Rehabilitation Act is the most complete and well-balanced legislation in the human services field.

The primary focus of the Act is to provide services to persons with mental and/or physical disabilities, enabling them to re-enter the workforce or obtain employment for the first time, and to become independent of public assistance, health care, or family support. The provision of these services results in a direct savings to government, as competitive work generates increased tax revenue, and as decreased dependence saves public assistance and other expenditures.

In the Rehabilitation Act, provisions are included for (1) a comprehensive and individually-tailored program of rehabilitation services to physically and/or mentally handicapped individuals; (2) an innovation and expansion program; (3) a training program; (4) a research program; (5) a special projects program; (6) a rehabilitation facilities program; (7) an employment program; (8) and a comprehensive services program for independent living.

This balanced emphasis embodies the elements necessary for a successful rehabilitation program to be provided through a nationwide network of public and private, community-based, service providers.

VOCATIONAL REHABILITATION SERVICES: BASIC STATE GRANTS

Section 110

FY 1987 CSAVR RECOMMENDATION........$1,379,400,000
FY 1987 AUTHORIZATION......................PENDING

Basic State Grants are the lifeblood of the Vocational Rehabilitation Program. This section of the Act funds the provision of vocational rehabilitation services to eligible individuals with mental and physical disabilities.

These Federal dollars, matched with state money at a ratio of 80% to 20%, permit State Rehabilitation Agencies to provide, or contract with private organizations and agencies to provide, individualized, comprehensive services to persons with mental and/or physical disabilities, for the purpose of rendering these individuals employed and independent.

Such services may include evaluation; comprehensive diagnostic services; counseling; physical restoration; prosthetic devices; various kinds of training and training supplies; placement; tools and equipment; transportation; post-employment services; and any other service needed to rehabilitate an individual into employment.

The people served by the Program include, but are not limited to, those with heart conditions, blind persons, deaf persons, amputees, persons with mental disabilities, diabetics, mentally retarded persons, and/or persons who have other chronic, disabling conditions incurred through accident, illness, or birth.

In the last year for which statistics are available, Fiscal Year 1984, the $1,037,800,000 appropriated for Basic State Vocational Rehabilitation served 936,180 disabled individuals, of which 225,772 were rehabilitated into employment.

Despite this expenditure, there still are not sufficient funds to serve all those eligible, disabled people who have the potential and desire to work and who need rehabilitation services to obtain employment and self-sufficiency.

Alarmingly enough, best estimates are that State Rehabilitation Agencies are able to serve only one out of every twenty people who are eligible.

To illustrate the declining resources available, the 1984

Report of the House Committee on Education and Labor, (98-298), states:

> "With economic factors alone considered, there was a 31 percent loss in purchasing power between 1979 and 1982. In real dollars, this amounted to a loss of $384,000,000."

State Rehabilitation Agencies, in carrying out the mandate of the Act to give priority of service to the rehabilitation of persons who are severely disabled, are finding that the costs, in time, effort and money, of serving this group are great -- much greater than the cost of rehabilitating the less severely disabled. This means that the Program is serving fewer people, while expending more money for adequate services, adequately-trained staff, adequate equipment, and adequate facilities.

In Fiscal Year 1985, 63.3 percent of all individuals served by State Rehabilitation Agencies were classified as "severely disabled" -- this is the highest percentage of persons with severe disabilities served in the history of the Program.

Unfortunately, the ability of the State Rehabilitation Agencies to provide necessary services is being impeded, due to declining resources and the costliness of serving persons identified as severely disabled (over 50 percent more costly than those to persons who are not severely disabled).

We urge the Congress to reverse this trend by appropriating funds based upon the need of persons with disabilities.

With these statistics in mind, and ever conscious of the vast need for services, the Council strongly urges that the Subcommittee provide appropriations for Basic State Vocational Rehabilitation Services in the amount of $1,379,400,000 for Fiscal Year 1987.

It is important to remember that the justification for higher funding levels stems from the purpose for which the money is spent--the prevention of an incalculable waste of human potential--a purpose on which no price tag can be placed.

Appropriating additional monies for Vocational Rehabilitation Services reduces the Federal Deficit.

Over the decades, Vocational Rehabilitation has more than paid for itself by helping persons with disabilities increase their earning capacity; by freeing family members to work; and/or by decreasing the amount of welfare payments, health services, and social services they might need; as well as by assisting them to become taxpayers.

The Congressional Budget Office has stated that "a reduction of funds for rehabilitation ... would generate increases in other parts of the federal and state budgets."

There is a return to Federal and state treasuries of ten dollars for every dollar spent for Rehabilitation Services, according to the Rehabilitation Services Administration of the Department of Education.

Funds appropriated for Vocational Rehabilitation are a sound investment of the Public's money.

COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING (TITLE VII)

FY 1987 CSAVR Recommendation.........$61,500,000
(Parts A,B,C)
FY 1987 Authorization...................PENDING

Part A, of Title VII of the Rehabilitation Act, establishes a State Grant Program to provide Comprehensive Services for Independent Living designed to meet the current and future needs of individuals, with disabilities so severe they do not presently have the potential for employment, but who may benefit from rehabilitation services which will enable them to "live and function independently."

When Title VII was enacted in 1978, a substantial new service delivery system, under Part A, was envisioned with sufficient funds available to develop effective long-range plans and services. Such funds have yet to be appropriated by the Congress.

The existing Independent Living Centers, under Part B, have proven--and continue to prove daily--the effectiveness of, and the need for, full implementation of the independent living concept.

However, we need desperately to supplement the services provided by the Centers. This can be done by appropriating adequate funds for Part A, to allow for an equitable state distribution procedure, in addition to providing a continuing funding base for the Part B Centers for Independent Living and the Older Blind Individuals Program under Part C.

To accomplish this, the CSAVR recommends an appropriation for FY 1987 of $61.5 million for Title VII -- providing $30 million for Part A; $26 million for Part B; and $5.5 million for Part C.

TRAINING GRANTS (Section 304(e)

FY 1987 CSAVR Recommendation..............$32,000,000
FY 1987 Authorization.........................PENDING

The specialized Rehabilitation Professions, such as those in the areas of counseling, work evaluation, rehabilitation medicine, rehabilitation nursing, and rehabilitation facility administration, do not have long histories. In fact, they are the creations of the training programs under the Rehabilitation Act.

The Council believes that these programs should continue to receive support, so that progress may continue to be made in upgrading the quality of professional services to persons with disabilities, and to develop new positions which are emerging with respect to providing services to persons identified as severely disabled.

The most critical training problem now facing State Rehabilitation Agenices is the need to upgrade the skills of rehabilitation personnel currently employed by the Agencies.

With new technologies, and with the continued emphasis on the provision of services to persons with severe disabilities, there is a serious need for priority to be placed on In-Service

Training for State Rehabilitation Agencies.

Since these training programs are so critical to the provision of quality services, and since they receive no major support from any other source, the CSAVR recommends that $32 million be appropriated under Section 304(e) for Fiscal Year 1987.

Money for Training is nothing less than an investment in increasing the quality of the provision of Vocational Rehabilitation Services to persons with mental and physical disabilities.

MONIES FOR DEMONSTRATION PROJECTS FOR SUPPORTED EMPLOYMENT

The Council wholeheartedly endorses the concept of Supported Employment and urges the Congress to continue adequate appropriations for National and State Demonstration Projects, in order that definitive information and statistics can be obtained relative to the costs, methods, factors, and universe of need involved in this effort.

Attached is a chart showing the recommendations of the CSAVR for the major Programs authorized by the Rehabilitation Act. While the CSAVR's Statement focuses on four major components of the Rehabilitation Act, the CSAVR supports adequate funding for all Sections of the Act, and wholeheartedly joins with the recommendations and rationale provided this Panel by other Organizatations and Advocates.

REHABILITATION ACT OF 1973, AS AMENDED
($ in millions)

Program	FY86 Appropriation	FY86 Post Sequestration	FY87 Authorization	Administration FY87 Budget	Recommendation
Basic State Grant	$1,190.0	$1,145.0*	Pending	$1,100.0	$1,379.4
Evaluation (Sec. 14)	2.0	1.914	Pending	.6	2.0
Training	27.0	25.839	Pending	15.0	32.0
National Institute of Handicapped Research	44.0	42.108	Pending	39.0	49.0
Innovation & Expansion	9.0	8.613	Pending	9.0	9.0
Independent Living					
Comprehensive State Services, Part A	11.0	10.527	Pending	---	30.0
Centers for Indepen. Living, Part B	23.0	22.011	Pending	22.0	26.0
Services to Older Blind Individuals, Part C	5.0	4.785	Pending	---	5.5
Service Projects:					
Client Assistance	6.7	6.4119	Pending	6.3	7.5
Special Demonstration Projects	20.2	19.33	Pending	14.6	30.6
Projects with Industry	15.2	14.5464	Pending	13.0	18.0
Special Recreation Programs	2.2	2.1054	Pending	---	4.5
Helen Keller National Center	4.3	4.1151	Pending	4.2	5.5
Archit. and Trans. Barriers Compliance Board	1.97	1.89	Pending	1.97	2.5

*This represents the cost of living reduction for section 110.

MONDAY, MAY 5, 1986.

REHABILITATION AND HANDICAPPED RESEARCH

WITNESS

VINCENT SCALIA, PRESIDENT-ELECT, NATIONAL COUNCIL ON REHABILITATION EDUCATION

Mr. NATCHER. Our next witness is Mr. Scalia. We are pleased to hear from you at this time.

Mr. SCALIA. Thank you, Mr. Chairman.

My name is Vincent Scalia, Chairman and President-Elect of the National Council on Rehabilitation Education.

NCRE is an organization composed of rehabilitation educators, researchers, training specialists and students. Our mission is to provide quality education and training to rehabilitationists who are working with a portion of the estimated 36 million disabled Americans in the United States and the five trust territories.

I appreciate the opportunity to testify before the committee. The written statement that has been submitted by our President-Elect, Dr. John Fonader, who was unable to be here today, is greatly appreciated and I would like to embellish on that with verbal testimony now.

Many analysts are optimistic about the economic forecast. Economists are saying times are good, predicting they may be getting better. I am not qualified to discuss the economy or economics and feel less so in making any kind of economic predictions about our future.

I am qualified and prepared to discuss with you some disturbing facts about employment of persons with disabilities. Current population surveys have been compiled and reported by the President's Committee on Employment of the Handicapped.

This data reports on only a segment of the disabled population, persons between the ages of 16 and 64, and more so those persons who are willing to reveal information about their disability.

From this group a remarkable 52 percent of all persons reporting a disability say they are prevented by that disability from working. Unfortunately, many of these people have not had the opportunity of seeking professional help, becoming employed by trained, qualified rehabilitation professionals. Since this census data reveals the working population data grew 20 percent between 1970 and 1980, while the number of people with disabilities that would handicap their employment grew 39 percent.

Today data reveals disabled persons are much less educated than others of working age. Only one disabled in every five has attended at least some college compared to one in three of the non-disabled. Regarding labor force participation, it is estimated that 58 percent of disabled men and 76.5 percent of disabled women are out of the labor force.

Two out of every three disabled men and four out of every five disabled women do not work is striking evidence of the difficulties disabled adults find in the labor market.

This data collected by household surveys and census, reported by the President's Committee on Employment of the Handicapped is powerful evidence that disabilities present a major barrier to employment.

There are some things that we must begin to acknowledge, that limitations in function is completely normal and increasing in numbers in many of our citizens, that one family in every three in the United States has at least one member with an obvious disability.

The major difference between persons with disabilities and other individuals who do not have disabilities is the number, the degree and the complexity of the barriers they face in trying to achieve their personal goals and fulfillment.

Even if economists are correct with their optimistic analyses and predictions, the facts show a disturbingly large number of Americans with disabilities need professional services to compete equally with the non-disabled to find employment and live independently.

The need for rehabilitation services delivered by competent professionals to equalize opportunities for the handicapped to compete with the non-disabled has never been greater. If the optimistic forecasts fall short of their predictions, we will find the handicapped citizens as a group have significantly diminished opportunities to compete equally with the non-disabled.

What is the importance of education? We spend a lot of time and I am sure you have heard a lot of testimony and have received a lot of information and data regarding services.

Somewhere along the line it seems that on occasion we fall short of informing people about pre-service education, post-employment training and research. Our experience in the last 30 years and research evidence demonstrates without a doubt that trained up-to-date rehabilitation professionals are essential for effective, efficient delivery systems.

The success of rehabilitation programs is dependent to a large degree on the availability and maintenance of competent professionals. The professional rehabilitation practitioner must possess special knowledges and skills. These knowledges and skills are acquired through specialized pre-service education and post-employment training.

If I might, I would like to give you some information regarding what pre-service and post-employment training is all about. Pre-service education is limited to preparing individuals for professional rehabilitation activities which must be performed.

Pre-service education emphasizes basic theory and general principles. It is viewed as a beginning, not an end, of professional training.

It is designed to orient the new practitioner to the present condition and prepare that practitioner for the future and change, change that our disabled citizens have to go through.

As a profession, vocational rehabilitation is not static but rather a rapidly changing and developing field. The very nature of the profession dictates that professional education must continue during a person's entire profession, then carries the responsibility for supplementing and extending the preparation obtained in pre-service settings.

Post-employment training includes both continuing education and in-service training in the State agencies that you have just heard from. Post-employment training follows a human resource development model and that model training is defined as that set of activities which is geared towards informing and enlarging the individual's repertoire of responses in any given situation.

Educational activities are designed to enhance the responses that the practitioner can bring to bear when faced with any issue or problem for a client.

Developmental activities are defined as that set of learning activities which help prepare those practitioners for uncertain futures, the same uncertain futures the clients are going to have to face.

They are often process centered and designed to bring about change over long periods of time. It is directed at training individuals for the field of vocational rehabilitation.

Post-employment education is directed at preparing rehabilitation practitioners for a specific job or position. Pre-service education is more than the inculcation of skills and techniques.

It is more than imparting information and knowledge. Pre-service education aims at developing the individual to think critically, analyze, synthesize and exercise judgment.

Post-employment education takes the practitioner in the work setting and provides the means or upgrades the ability of that person to function effectively in a specific job.

Pre-service education addresses identified shortages of rehabilitation personnel while post-employment education services to upgrade knowledge and skills of the current personnel.

An illustration of that might be seen with medical care. I don't think anyone in this room—I don't think anyone outside this room would be willing to go to a physician or have an attending physician who is not properly trained or current in medical advancements.

I take that one step further, I think. There isn't a person in this room that would be willing to take their care to a mechanic that has not been properly trained or up-to-date in the latest advancements in mechanics. Why then should we allow our disabled citizens to be attendant to someone who is not properly trained or is not updated periodically.

We should insist and guarantee that our disabled citizens receive services from professionally trained practitioners who are abreast of current advancements.

Rehabilitation training was authorized by Congress in 1954. The result has been an impressive network of pre-service education, post-employment training programs which are responsive to the preparation and continuing training needs of the practitioner and enabled practitioners to provide comprehensive services to this Nation's handicapped.

The Federal and State rehabilitation program established under the Rehabilitation Act includes a careful balance of research, education, training and service delivery components, each of which strengthens and reinforces the other.

The success of the rehabilitation program and the quality of services to our handicapped citizens depends on the availability and maintenance of competent personnel.

Congressional recognition and commitment to a strong rehabilitation training program indicating congressional intent is not to curtail Federal involvement in rehabilitation training but to strengthen and improve the effectiveness of the program.

The Administration's funding request and policies run counter to this intent and threaten the viability of rehabilitation training and the quality of services available to the disabled. Following the course proposed by the Administration, the supply of trained rehabilitation personnel will be reduced by fewer graduates and the ability to upgrade the skills of employed personnel will be ignored, diminishing the quality of services to disabled citizens.

The National Council on Rehabilitation Education recommends that Congress fully fund the rehabilitation training program at the $32 million level. Low visibility groups such as the disabled tend to lose resources unless funds re specifically targetted to their needs.

Special purpose monies continue to serve the special purposes for which it was appropriated and does make a difference on who gets served and the quality of service.

With full funding, citizens with disabilities can be the beneficiaries of quality services. Disabled persons deserve the opportunity and have the right to receive rehabilitation services from trained professionals.

State agencies need to employ and maintain competent practitioners. Rehabilitation practitioners need to be graduates of recognized pre-service education programs and recipients of post-employment training to serve as competent professionals. If the optimistic economic analyses and forecasts are correct, let us ensure disabled Americans will have an equal opportunity to live independently and live well.

It is the hope of the National Council on Vocational Rehabilitation, along with our Council and State Administrators of Vocational Rehabilitation, the Association of Educators for Rehabilitation Facility Programs and the National Rehabilitation Association, that the committee will approve full funding to support our efforts and to train rehabilitation practitioners to meet the needs of the Nation's handicapped.

Thank you for the opportunity to explain the importance of this program.

Mr. NATCHER. Thank you, Mr. Scalia. We appreciate your appearance. You have given us an excellent statement.

Thank you very much.

[The statement of Mr. Scalia follows:]

STATEMENT OF

VINCENT SCALIA, PRESIDENT-ELECT

National Council on Rehabilitation Education

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE

ON

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION

RELATIVE TO THE

FY 1987 APPROPRIATIONS FOR

PROGRAMS AUTHORIZED BY THE REHABILITATION

ACT OF 1973, AS AMENDED

NC
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MAY 5, 1986

OFFSET
CAMERA COPY

Mr. Chairman, Members of the Subcommittee, ladies and gentlemen; my name is Vincent Scalia, Chairman, Department of Human Services, at the University of Northern Colorado and President-Elect of the National Council on Rehabilitation Education (NCRE). NCRE is an organization composed of rehabilitation educators, researchers, training specialists and students. Our mission is to provide quality education and training to rehabilitationists who are working with a portion of the estimated 36 million disabled Americans in the United States and the five trust territories. The National Council on Rehabilitation Education works in tandem with the American Rehabilitation Counseling Association (ARCA), the National Rehabilitation Counseling Association (NRCA), the National Rehabilitation Association (NRA), the President's Committee on the Employment of the Handicapped (PCEH), the Council of State Administrators of Vocational Rehabilitation (CSAVR), the National Council of State Administrators of the Blind (NCSAB), and other members of the Rehabilitation Coalition. Over the years our membership has assisted the Rehabilitation Services Administration (RSA) of the U.S. Department of Education by conducting surveys and studies related to our training mission and the needs of the State/Federal Vocational Rehabilitation Program. Many of our NCRE member institutions are conducting research with the support and participation of the membership to improve training and/or the delivery of services to disabled citizens. Currently, the NCRE organization is conducting a three-year, nation-wide research study of rehabilitationists which will influence the direction of training.

I appreciate the opportunity to testify before the Committee and to submit our statement for the record in support of full funding for rehabilitation education, training and research.

First, I would like to address the problems of the disabled Americans that we serve. Disabled Americans need rehabilitation services to live independent lives and/or find employment. In a recent Louis Harris and Associates Poll, two-thirds of disabled individuals between the ages of 16 and 64 are unemployed. Disabled Americans are much poorer than non-disabled Americans. Only 1 disabled adult in every 5 has taken some college courses compared with 1 in 3 non-disabled adults. Census data indicated the working population grew 20% between 1970 and 1980; during that same time period the number of people with disabilities - that is disabilities that would be a handicap to their employment - increased by 39%. With the advances of medical science, many disabled citizens are no longer dying from disabling diseases; however, many have extensive functional limitations. These limitations create more barriers to employment. The President's Committee on Employment of the Handicapped has indicated that as a group, disabled citizens do not have the same opportunities as non-disabled when competing for employment. Likewise, this limits their opportunity to live independent lives.

The "computerization" of America will compound the difficulties the disabled citizens have in getting and keeping jobs. The labor market trends of the next decade point toward more technical, scientific and professional jobs while unskilled and semiskilled jobs will decrease. College and/or technical training will be required for more entry-level positions. These requirements will place the disabled population at a disadvantage. The rehabilitation professionals will find job placement of the disabled more challenging than in past years. It is imperative that rehabilitation professionals are qualified to help disabled citizens in this changing labor market. For example, qualified rehabilitation professionals need to be knowledgeable of how robots in the work place influence the number and kind of jobs available. Because work has become less physical, does not make it more available to disabled citizens; the educational and technical skills often prevent disabled citizens from meeting the job requirements. Untrained or poorly trained professionals will not be able to meet these challenges, nor will the rehabilitation professionals who do not stay current through in-service or continuing education training. It is also a certainty that the rehabilitation needs of the disabled will not be met if there is a shortage of training monies or a shortage of rehabilitation personnel.

The President has recommended $15 million for training for the Fiscal Year 1987 under the Rehabilitation Act of 1973. The 1986 appropriations is $27 million and the Rehabilitation Coalition has recommended $32 million for 1987. The National Council on Rehabilitation Education supports the $32 million level of funding for Rehabilitation Training due to the current and future shortages of qualified rehabilitation professionals.

The justification is as follows:

1. Fewer than 50% of rehabilitation counselors currently employed by state vocational rehabilitation agencies meet the definition of "qualified", i.e., they do not have a masters degree or are not certified (thereby impairing the quality of rehabilitation services).
2. The 1983 Menz Study of rehabilitation personnel needs of rehabilitation facilities, while employing an average of 23 rehabilitation professionals in 1980, projected the need for 43 such personnel by 1990 - an 87% increase in the need for trained, qualified personnel.
3. The published data of the Bureau of Labor Statistics shows shortages of rehabilitation professionals across the nation.
4. Shortages of qualified rehabilitation professionals were also indicated in the 1984 National Manpower Needs Assessment, commissioned by the Rehabilitation Services Administration (RSA).
5. Individual states reported similar results. In Washington State, for example, three manpower surveys were completed in the last five years. The data from all three indicate a need for additional training for current staff and additional qualified rehabilitation professionals.

Disabilities present major barriers to employment and to independent living. These barriers can be overcome with the services of qualified rehabilitation professionals - functional professionals. Our experience and research evidence over the last thirty years demonstrate without a doubt that trained rehabilitation professionals are essential for an effective, efficient delivery of services to disabled citizens. The success of the rehabilitation program is dependent to a large degree on not only availability, but also on the maintenance of competent professionals. The President's 1987 request for $15 million would drastically reduce rehabilitation training (approximately 50%). This Presidential request would severely curtail pre-service and continuing education. The supply of trained rehabilitation personnel will be reduced by fewer graduates and the ability to upgrade the skills of employed personnel will be severely limited, diminishing the quality of the services to disabled citizens. The only way to guarantee that our disabled citizens receive services from qualified rehabilitation professionals who are kept abreast of current advancements is to provide full funding for rehabilitation education and training.

The National Council on Rehabilitation Education respectfully requests full funding for rehabilitation training. Mr. Chairman, NCRE is prepared to assist you and your Committee in any way possible to achieve our mutual goal of ensuring quality rehabilitation services to disabled citizens through the preparation of qualified rehabilitation professionals. On behalf of the National Council on Rehabilitation Education, thank you for this opportunity to explain the importance of Rehabilitation Training and its relevance to the rehabilitation of disabled citizens.

MONDAY, MAY 5, 1986.

REHABILITATION SERVICES

WITNESS

BARBARA ROHAN, PRESIDENT, REHABILITATION ASSOCIATION, WEST SPRINGFIELD, MASSACHUSETTS, REPRESENTING THE NATIONAL ASSOCIATION OF REHABILITATION FACILITIES

Mr. NATCHER. Our next witness is Mrs. Barbara Rohan.

Mr. Conte, I yield to you.

Mr. CONTE. Thank you, Mr. Chairman.

I want to add that it is a particular pleasure for me to welcome Mrs. Barbara Rohan before this Committee today. Mrs. Rohan is a constituent of mine.

I knew her father very well. Her father came from my home town, a very distinguished fireman, chief of the fire department in Pittsfield. Now she resides in another part of my district. She lives near my oldest daughter, Michelle. She works in West Springfield which makes her advice as good as gold for me and, Mrs. Rohan, we welcome you, and it is a pleasure to have you here.

Mrs. ROHAN. Thank you very much, Mr. Conte. Thank you, Mr. Natcher.

My name is Barbara Rohan. I am President of Rehabilitation Associates in Springfield, Massachusetts. I am also a rehabilitation nurse and a clinical specialist.

The program I am associated with has offices in West Springfield, Massachusetts, and Austin, Texas. We serve approximately 65 out-patients per day with a wide variety of medical rehabilitation services. We deal with pediatric and geriatric problems, severe head trauma and spinal cord injuries. We also work with industrial health programs and sports medicine.

I am here on behalf of the National Association of Rehabilitation Facilities. NARF is the national voluntary membership organization of community-based rehabilitation facilities with over 600 rehabilitation facilities and 23 affiliated State chapters. These rehabilitation facilities serve well over 700,000 persons with disabilities annually.

The membership includes freestanding rehabilitation hospitals, rehabilitation units of general hospitals, comprehensive outpatient rehabilitation facilities, of which I am a member, developmental work centers and vocational facilities as well. We are very pleased to be able to testify before you today on issues of concern to us in the fiscal year 1987 Labor-HHS Education Appropriations Bill.

Without any changes in the current law, medicare spending in fiscal year 1987 will total approximately $82 billion. The President's budget request calls for legislative and regulatory reforms to reduce spending under medicare by approximately $5.2 billion.

The majority of the spending reductions are aimed at health care providers. The majority of NARF's members participate in the medicare program. According to a recent study conducted by NARF, about 50 percent of their revenues come from medicare.

Sixty percent of the Administration's spending reductions are targeted on medicare service providers and would limit hospital capital cost payments, medical education, physician reimbursement and payment for non-physician services, including rehabilitation.

NARF opposes continued reductions in payments to medicare providers. NARF strongly supports the full budget request for medicare contractors and urges the committee to appropriate additional funds specifically for claims processing and beneficiary and provider services. In the last two years, the turnaround time for claims submitted by rehabilitation providers has increased dramatically.

CORFs provide comprehensive outpatient rehabilitation services to eligible medicare beneficiaries under part B. These facilities, which are usually located close to the beneficiary's home and allow them to come home from the hospital, are receiving increasing numbers of referrals as a result of implementation of prospective payment system. Many of these facilities are smaller with revenues generally below $1 million.

They provide a vital service within their communities by providing these comprehensive rehabilitation services. However, many of these facilities simply are not being paid by the intermediaries designated in each state to process CORF claims.

Intermediaries tell CORFs that they simply are not going to process the claims because they have too many other responsibilities; are losing claims, requiring the facility to submit them two and three times; and are continually requesting additional information two and three times in a processing of one claim. The net result is that facilities are not being paid in a timely manner, if at all.

One facility in Connecticut currently has over $120,000 in billings outstanding and has not been paid since October despite repeated meetings with the intermediary. Two CORF's have not been paid since October. Another facility with over $100,000 in outstanding claims has been forced to get a bank loan, as I have.

Therefore, Mr. Chairman, we urge that the committee make additional funds available for claims processing and payment and furthermore that the committee require that payment at least for these types of outpatient providers be required to be made promptly.

NARF opposes the Administration's proposal and urges the committee to provide full funding for the medicaid program. A cap on future Federal medicaid outlays would place a disproportionate share of the burden of reducing the Federal deficit on those who are poor, elderly and disabled and are the most vulnerable segment of society. Additionally, such a cap would lock in existing interest inequities in Federal aid for health and health related services to medicaid eligible recipients. Therefore, NARF urges that the President's fiscal year 1987 recommendations for medicaid be rejected.

The Rehabilitation Act of 1973 remains the foundation for vocational services to persons with disabilities. The Administration has asked that the basic grants to the States be cut back to the 1985 level. This is incomprehensible for a program whose primary aim is to put disabled persons into competitive job in the community, saving State and Federal Government millions of dollars over the cost of maintaining disabled persons on welfare programs.

Rather than allow cuts to this program, NARF urges this committee to increase funding for basic State grants to $1379.2 million. This modest increase over current level will allow more persons with disabilities to be served and ultimately save a tremendous amount of money.

The program within the Rehabilitation Act which deserves your special attention is Projects With Industry. A recent report to Congress from the Rehabilitation Services Administration found that PWI was an efficient and very cost effective means of placing persons with disabilities into competitive community jobs.

The report also said that Congress should decide whether it is time to establish PWI as a service delivery program. We feel that the time has come based on the study and the best way to change from the current demonstration status is to provide sufficient funding to significantly expand the program.

The study found that PWI graduates from one year increased their earnings $1.263 million a week or over $65 million a year. This is very impressive for a program that was funded at $13 million at the time. Appropriations for PWI for fiscal year 1987 should be no less than $20 million.

Training of rehabilitation professionals is another area of the Rehabilitation Act that deserves special scrutiny. The Administration has asked for a reduction of over 40 percent. There has been an erosion of training resources during the past few years which if continued will jeopardize the quality and quantity of services to persons with disabilities. Last year this committee helped restore funding to this important function. We ask again that adequate funding be provided to ensure the future for disabled persons.

NARF strongly recommends that funding for NIHR increased to $49 million for fiscal year 1987. This level of funding would enable the needed growth in center programs, support 04 new research grants, comply with Congress' intent to increase funds for expanded support for existing center and additional field initiated research grants, and allow the institute to work with NIHR in developing medical research areas such as pediatric and geriatric rehabilitation and enable the research training, which was funded under the fiscal year 1986 appropriations fill to be furnished.

This committee has expressed concern that the NIHR has not given sufficient priority to people with head injuries and has accordingly directed NIHR to seek proposals addressing these areas. In contrast to the Administration's request, this recommendation would allow for new and expanded work regarding high risk infants, burn rehabilitation, spinal cord injury and employment of people with mental illnesses.

Mr. Chairman, thank you for the opportunity to appear before you and I will be happy to answer any questions.

Mr. **NATCHER**. Thank you very much. You have given an excellent statement.

[The statement of Mrs. Rohan follows:]

NARF

NATIONAL ASSOCIATION OF REHABILITATION FACILITIES

John E. Lapidakis
President

John A. Doyle
Executive Director

TESTIMONY OF

BARBARA ROHAN, PRESIDENT

RE-HAB ASSOCIATES, INC.

WEST SPRINGFIELD, MASSACHUSETTS

ON BEHALF OF THE

NATIONAL ASSOCIATION OF

REHABILITATION FACILITIES

BEFORE THE

SUBCOMMITTEE ON LABOR--HHS EDUCATION

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES
WASHINGTON, DC

MAY 5, 1986

P.O. Box 17675, Washington, D.C. 20041 • (703) 556-8848

Good morning, Mr. Chairman. My name is Barbara Rohan. I am president of Rehabilitation Associates, Inc. in Springfield, Massachusetts. I am also a rehabilitation nurse and a clinical specialist. The program I am associated with has offices in West Springfield, MA and Austin, Texas. We serve approximately 65 out patients per day with a wide variety of medical rehabilitation services. We deal with pediatric and geriatric programs, severe head trauma and spinal cord injuries. We also work with industrial health programs and sports medicine.

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The membership includes freestanding rehabilitation hospitals, rehabilitation units of general hospitals, comprehensive outpatient rehabilitation facilities, developmental work centers and vocational facilities as well. We are very pleased to be able to testify before you today on issues of concern to us in the FY 1987 Labor-HHS Education Appropriations Bill.

Medicare

Currently, the Medicare program covers approximately 29 million elderly people representing about 98% of all Americans over the age of 65. In addition, Medicare covers approximately 3 million people with disabilities. Without any changes in the current law, Medicare spending in FY 1987 will total approximately $82 billion. The President's budget request calls for legislative and regulatory reforms to reduce spending under Medicare by approximately $5.2 billion. The majority of the spending reductions are aimed at health care providers.The majority of NARF's medical members participate in the Medicare program. According to a recent study conducted by NARF, about 50% of their revenues come from Medicare.

Sixty percent (60%) of the Administration's spending reductions are targeted on Medicare service providers and would limit hospital capital cost payments, medical education, physician reimbursement, and payment for nonphysician services, including rehabilitation.

The Administration proposes to make various changes in program management. The 1987 budget proposes to increase funding for Medicare contractors for claim processing/beneficiary and provider services by $47 million. The budget documents note that an additional 33 million claims a 9% increase are expected to be processed in 1987. The conference report for the FY 1986 appropriations bill provided funding of approximately $963 million for program management. However, $41 million of this amount was sequestered under the initial sequestration order pursuant to P.L. 99-177 and $2 million has been proposed for a recision.

NARF opposes continued reductions in payments to Medicare providers. NARF strongly supports the full budget request for Medicare contractors and urges the Committee to appropriate additional funds specifically for claims processing and beneficiary and provider services. In the last two years, the turnaround time for claims submitted by rehabilitation providers has increased dramatically. For example, there are currently approximately 85 comprehensive outpatient rehabilitation facilities (CORFs) in the country. According to a national survey conducted by our organization, the payment time for claims submitted by these organizations runs from as long as 60 to 120 days.

CORFs provide comprehensive outpatient rehabilitation services to eligible Medicare beneficiaries under part B. These facilities, which are usually located close to the beneficiary's home and allow them to come home from the hospital, are receiving increasing numbers of referrals as a result of implementation of the prospective payment system. Many of these facilities are smaller with revenues generally below $1 million. They provide a vital service within their communities by providing these comprehensive rehabilitation services. However, many of these facilities simply are not being paid by the intermediaries designated in each state to process CORF claims. Intermediaries tell CORFs that they simply are not going to process the claims because they have too many other responsibilities; are losing claims, requiring the facility to submit them two and three times; and are continually requesting additional information two and three times in the processing of one claim. The net result is that facilities are not being paid in a timely manner, if at all. This creates dramatically difficult cash flow problems for these facilities and unfortunately has an adverse impact upon the beneficiaries receiving services. One facility in Connecticut currently has over $120,000 in billings outstanding and has not been paid since October despite repeated meetings with the intermediary. Two CORF's have not been paid since October. Another facility with over $100,000 in outstanding claims has been forced to get a bank loan.

Therefore, Mr. Chairman, we urge that the Committee make additional funds available for claims processing and payment and furthermore that the Committee require that payment at least for these types of outpatient providers be required to be made promptly.

Furthermore, declining financial support to Medicare providers and the imposition of rigid service limitations continues to endanger the ability of beneficiaries to receive appropriate, high quality care.

Medicaid

Approximately 23 million Americans who are elderly, blind and disabled, and low-income receive health care benefits through the Federal-state medical assistance program known as Medicaid. Under current law, Medicaid outlays for all purposes are expected to increase by $1.4 billion between FY 1986 and FY 1987. The Administration has, however, proposed legislative changes to decrease program outlays by approximately $1.3 billion in FY 1987. These savings would be reached by limiting Federal Medicaid expenditures to $23.6 billion in FY 1987, compared to an estimated $24.8 billion required under current law. The Administration proposals assumes $1.3 billion as a result of a statutory spending limitation or Medicaid cap and an additional $260 million in savings due to administrative cost limitations and several other changes. In addition, the growth of Federal expenditures in future fiscal years would be restricted to increases in the medical care component of the Consumer Price Index. Within the overall spending ceiling or cap, each state would be entitled to receive the same proportional share of Federal funds as it expended in 1985. The administration has proposed a one-time $300 million "hardship" fund to assist states which, for reasons beyond their control, exceed their Federal spending ceilings in FY 1987.

NARF opposes the Administration's proposal and urges the Committee to provide full funding for the Medicaid program. A cap on future Federal Medicaid outlays would place a disproportionate share of the burden of reducing the Federal deficit on those who are poor, elderly and disabled and are the most vulnerable segment of society. Additionally, such a cap would lock in existing interstate inequities in Federal aid for health and health related services to Medicaid eligible recipients. Therefore, NARF urges that the President's FY 1987 recommendations for Medicaid be rejected.

Rehabilitation Act

The Rehabilitation Act of 1973 remains the foundation for vocational services to persons with disabilities. The Administration has asked that the basic grants to the states be cut back to the 1985 level. This is incomprehensible for a program whose primary aim is to put disabled persons into competitive jobs in the community, saving state and Federal government millions of dollars over the cost of maintaining disabled persons on welfare programs. Rather than allow cuts to this program NARF urges this Committee to increase funding for basic state grants to $1379.2 million. This modest increase over current level will allow more persons with disabilities to be served and ultimately save a tremendous amount of money.

A program within the Rehabilitation Act which deserves your special attention is Projects With Industry. A recent report to Congress from the Rehabilitation Services Administration found that

PWI was an efficient and very cost effective means of placing persons with disabilities into competitive community jobs. The report also said that Congress should decide whether it is time to establish PWI as a service delivery program. We feel that the time has come based on the study and the best way to change from the current demonstration status is to provide sufficient funding to significantly expand the program. The study found that PWI graduates from one year increased their earnings $1.263 million a week or over $65 million a year. This is very impressive for a program that was funded at $13 million at the time. Appropriations for PWI for FY 1987 should be no less than $20 million.

Training of rehabilitation professionals is another area of the Rehabilitation Act that deserves special scrutiny. The Administration has asked for a reduction of over 40%. There has been an erosion of training resources during the past few years which if continued will jeopardize the quality and quantity of services to persons with disabilities. Last year this Committee helped restore funding to this important function. We ask again that adequate funding be provided to insure the future for disabled persons.

National Institute of Handicapped Research

The National Institute of Handicapped Research conducts research and demonstration projects and related activities concerning rehabilitation of persons with disabilities. NIHR supports research and training centers, rehabilitation engineering centers, research grants, fellowships and research demonstration projects. Research is now being funded at more than 100 educational institutions and in various areas of interest including spinal cord injury, arthritis, heart disease, mental illness, deafness, blindness and head trauma.

The Administration's FY 1987 budget request is for $39 million. This level of funding is the same as that requested for FY 1985.The FY 1986 appropriations bill provided for funding of $44 million. Furthermore, the President's budget request would only fund continuation costs of existing grants.

NARF strongly recommends that funding for NIHR increased to $49 million for FY 1987. This level of funding would enable the needed growth in center programs, support 40 new research grants, comply with Congress's intent to increase funds for expanded support for existing center and additional field initiated research grants, and allow the institute to work with NIHR in developing medical research areas such as pediatric and geriatric rehabilitation and enable the research training, which was funded under the FY 1986 appropriations bill to be furnished.

This committee has expressed concern that the NIHR has not given sufficient priority to people with head injuries and has accordingly directed NIHR to seek proposals addressing these areas. In contrast to the Administration's request, this recommendation would allow for new and expanded work regarding high risk infants, burn rehabilitation, spinal cord injury and employment of people with mental illness.

Other Recommendations

Rehabilitation facilities use a wide variety of Federal programs to help disabled persons improve themselves through employment and increased independence. Attached to this statement are recommended funding levels which NARF endorses. These recommendations have been endorsed by more than 30 national organizations that represent or provide services to disabled persons.

NARF staff would be glad to answer any questions or provide any additional information the Subcommittee may need.

NARF RECOMMENDATIONS FOR FY 1987 APPROPRIATIONS
(in millions of dollars)

REHABILITATION ACT PROGRAMS	
State grants	1379.2
Training	32
Independent Living	61.5
Special Demonstrations (inc. Supported Emp.)	30.60
Projects With Industry	20
Special Recreation	4.5
Client Assistance	7.5
Research (NIHR)	49
Innovation and Expansion	9
SPECIAL EDUCATION	
State and Local Grants	1435.6
Pre-school incentive and intervention	200
Transitional Programs	7.0
DEVELOPMENTAL DISABILITIES	
State grants	56.5
Protection and Advocacy	15.5
University Affiliated Facilities	10.1
Special Projects	3.1
JOB TRAINING PARTNERSHIP ACT	
Title II	1969.4
Pilots and Demonstrations	40.7
SMALL BUSINESS HANDICAPPED LOANS	20
NATIONAL COUNCIL ON THE HANDICAPPED	.850
SECTION 202 HUD LOANS	656.9
COMMUNITY DEVELOPMENT BLOCK GRANT	3252.1
TITLE XX BLOCK GRANT	3300

CHRONOLOGY OF EVENTS

1982-1983 January, 1982 - Applied for certification as Medicare provider.

Approved in April 1982 as an outpatient PT/SP Program Provider.

Informed at that time by H.C.F.A. - Region I that C.O.R.F. Regs. were not available, but were assured that we would qualify at time of final approval by H.C.F.A.

Timely Cost Reports (Form 2088) filed for F/Y 1982/3, and 83/4, for OPT/SP.

On January, 1984 we had to request a retroactive acceptance as a C.O.R.F., as it was not forthcoming.

On April 5, 1984 we received a letter, from H.C.F.A. Region I, advising us that we had been accepted as a C.O.R.F. with an effective date of coverage as of January 24, 1984. We were also advised that retroactive certification would be issued under separate letter.

Simultaneously on April 5, 1984 a letter from H.C.F.A. acknowledging withdrawal of the Agency from OPT/SP, (effective 1/24/84, date of approval as C.O.R.F.), and requesting that we make arrangements with BC/BS for a final cost report, and advising us that we would now have Aetna as the intermediary.

April, 1984 - Contacted BC/BS to make arrangements for a Final Cost Report. Questioned dates of approval as a C.O.R.F. Y/E was Jan. 31, while approval as C.O.R.F. and withdrawal as OPT/SP was Jan. 24. Blue Cross suggested that since only a few days, that Re-Hab should file through the end of the period.

Any questions relative to retroactivity and collection for services provided and not covered under OPT/SP, but reimbursable under C.O.R.F. (i.e. OT) should be addressed with the new intermediary. Audit Reim. suggests not pursuing retroactive payment as we would have to reimburse old intermediary for payments under OPT/SP then rebill new intermediary for services rendered. Re-Hab choose not to follow this route as it would cause financial hardship on the agency.

Contacted new intermediary enquiring as to billing procedures, cost reporting requirements, and establishment of interim reimbursement rate.

May, 1984 On site visit by member of audit/reim. div. of new intermediary. Historical and pro-forma financial and statistical data projected. Budgets given to intermediary for determination and establishment of interim rate. - All billing held pending rate approval.

June, 1984 Received confirmation of interim reimbursement rate. Bills from Feb. 1984 on, can now be processed.

July, 1984 Request by Agency to change fiscal reporting period from a January 31 year end to a September, 30th year end.

August, 1984 Approval by intermediary of fiscal year end change.

October, 1984 First check received for services originating in Feb. 1984. Claims Administration states that due to delay in notification of rate - claims could not be processed - - once process and rate had been established, claims were being processed, with a turnaround time of approximately thirty days, from date of billing to receipt of check.

December, 1984 T/C to audit/Reim. section RE: Filing of Cost Report no "C.O.R.F." form - on automatic extension.

May, 1985 T/C to audit/Reim. section RE: Filing of Cost Report - Still no forms. Informed that Agency would have 60 days to complete and return when forms are finally issued.

September, 1985 Training session to review billing procedures for completion of UB-82.

Filed Cost Report for period ending Sept. 1984.

October, 1985 Billing addressed on separate addenda.

December, 1985 Filed Cost Reports - Period ending Sept., 1985.

February, 1986 Received "Confirmation of Reimbursement Rate" as of Feb. 17, 1986 - Reimbursement rate to 100% on all claims - Based on cost report from 9/30/84.

April, 1986 No settlement as yet on cost reporting for 1985.

MEDICARE BILLINGS

Oct. 1985 Billings totaling $3,290 - for 12 patients submitted on November 19, 1985 - 9 claims paid on February 6, 1986 - (3 months later - 3 claims denied due to date sequencing on M.D. orders.

Nov. 1985 Billings - $7,955 - 16 patients - submitted 12/5 13 claims rejected - 1 paid in February. (2 months after billed) 2 paid in April (4 months after billed). Claims rejected due to date sequencing on M.D. orders.

Dec. 1985 Billings - $5,010 - 11 patients - Submitted 1/9/86 - 3 Billings paid in full in April (3 months after billing). 1 Bill partially paid April (3 months after billing). 2 Bills partially paid March (2 months after billing). 5 Bills still pending - further information requested on these five bills on April 7, 1986 - Bills returned to facility (3 months after billing submitted).

Jan. 86, Feb. 86, March 86 At this time claims are still pending.

1. Intermediary claims that due to H.C.F.A. Regs. mandating review of ALL C.O.R.F. claims - they have a large backlog, and we will just have to wait.
2. C.O.R.F. mandates for service as published in Federal Register differ from those being used under interpretive guidelines which are being interpreted ambiguously by intermediary claims personnel.

March 10, 1986 Letter received from Superintendent of Claims Administration outlining the criteria for documentation required to process billing.

April 22, 1986 Letter received from Manager of Claims Administration negating letter received on March, 1986 and outlining another criteria.

N.B. Bills originally submitted were returned for provision of documentation as described in March letter. They were subsequently returned with a request for completion of billing questionaire per April letter.

MONDAY, MAY 5, 1986.

PREVENTIVE HEALTH SERVICES BLOCK GRANT

WITNESSES

HARRY TETER, JR., DIRECTOR, ATLANTIC EMS COUNCIL
MICHAEL DYER

Mr. NATCHER. Our next witness is Mr. Harry Teter. Come around, Mr. Teter. We will be pleased to hear from you at this time.

Mr. TETER. Thank you, Mr. Chairman. Today I am accompanied by Mr. Michael Dyer, who works with me in the emergency medical services field.

I wish to bring regrets for Dr. Cowley. He is not able to be here for medical reasons. He has a dental problem.

We are here today to urge the committee to give full appropriations to the preventive health care block grant.

We have a statement which I will submit for the record. I have a few very brief comments. For the past five years, the emergency medical services program has been a part of the block grant. Prior to then, we had a categorical program to address this problem.

I would like to say very briefly what the problem is, because when we talk about emergency medical services, we are talking about really the problem of trauma, those people who are in accidents, who are suffering life-threatening injuries. These people need help immediately, the type they cannot get on their own, the type only medical emergency services systems can provide. Without these systems, people die or have long-term injuries. With assistance, we have proved dramatically that they are either rescued from death or that they receive proper care and return to productive lives.

Last year, over 100,000 people died in this country due to traumatic injuries, and over 2,000,000 people were injured. The cost to this country is roughly $90,000,000. You add in all of the direct and indirect costs, emergency medical services, the pre-hospital and the hospital care that is absolutely critical is what is needed throughout this country.

As I said, for a few years, from 1973 until 1981, we had a specific program to build a network of emergency medical services systems across this country. Unfortunately, before that was completed that program was merged into the block grant. Now, fewer dollars are going into emergency medicine, yet the problem is still with us. We urge the committee to give the appropriations to this block grant, and also urge that in the block grant that the health services portion of those programs be addressed in more detail than is being done right now.

Emergency medicine is critical to your safety and to my safety.

I thank you very much, Mr. Chairman. I will be glad to give any other statements or comments that you might desire.

Mr. NATCHER. Mr. Teter, we want to thank you for your appearance before our committee. You have given us an excellent statement.

[The statement of Mr. Teter follows:]

STATEMENT OF

R ADAMS COWLEY, M.D.
Director of the Maryland Institute
for Emergency Medical Services Systems
and
Chairman, Atlantic EMS Council

and

HARRY TETER, JR.
Director, Atlantic EMS Council

before

HON. WILLIAM H. NATCHER
Chairman
Subcommittee on Labor, Health and
Human Services and Education Appropriations

May 5, 1986

Mr. Chairman, on behalf of the Atlantic Emergency Medical Services Council and the Maryland Institute for Emergency Medical Services Systems we appreciate the opportunity to appear before you today to testify in support of full appropriations for the Preventive Health Services Block Grant. The Atlantic EMS Council is composed of emergency medical services representatives from the states of New Jersey, Pennsylvania, Delaware, Maryland the District of Columbia, Virginia and West Virginia. The Maryland INstitute for EMS Systems is a leading developer of EMS. It is the home of one of the world's leading Shocktrauma Centers and hosts the National Study Center for Trauma and EMS.

Cowley, Teter Testimoney

Since categorical funding was eliminated five years ago emergency medical services has not fared well in the Preventive Health Services Block Grant. For example in FY 1983 all but one state reported cuts in EMS funding. Those cuts ranged from 7% to 84% according the the Center for Disease Control which administers the block grant. The Government Accounting Office, in reviewing state implementation of the block grant reported that a number of states had discontinued funding for EMS "because state officials believed it to be a local responsibility."

Mr. Chairman, the fact is that decreases in federal support for EMS do not make sense in light of the program's effectiveness and the magnitude of the problem. Trauma is the greatest killer of our young, those from ages 1 - 40 years old, and the third overall greatest killer. EMS is primarily concerned with the critically ill and injured victims of trauma. Time is critical and a victim treated by an EMS team will receive initial care and be in the definitive medical center within 60 minutes. If comprehensive EMS services are available many who would otherwise die are saved.

Unfortunately, Mr. Chairman, this extraordinary success is applicable only to those areas that have the benefit of EMS availability. Creation of new facilities, expansion of existing services, and estabilishment of linkages within the EMS network are necessary for optimal implementation. Systems must cover broad areas rather than small localities because victims may require the services of a variety of specialized facilities such as a shocktrauma center, a burn unit, or a pediatric emergency facility. Traditional geographical and political boundaries are irrelevant in most cases. Provision of emergency medical services is not solely a local issue. The Federal role is particularly significant because the most effective system requires interstate networking with a coordinated national focus. The Federal commitment to supporting EMS must be made if we are to realize its full potential.

Accordingly, we recommend targeting funding for EMS. Specifically we request the appropriations committee earmark 25% of the FY 1987 Preventive Health Services Block Grant funds for EMS. Those monies are essential if new state-of-the-art services are to be established nationwide.

Thank you for this opportunity to comment and we will be happy to answer any questions.

MONDAY, MAY 5, 1986.

BILINGUAL EDUCATION

WITNESS

GERDA BIKALES, EXECUTIVE DIRECTOR, U.S. ENGLISH

Mr. NATCHER. Our next witness is Ms. Gerda Bikales. We will be pleased to hear from you at this time.

Ms. BIKALES. I thank you for the opportunity to present the views of U.S. English on funding needs for bilingual education in fiscal year 1987.

We first appeared before you in 1983, when our membership numbered 300. By 1984, we had 35,000 members; in 1985, this number had gone up to 100,000; we now have some 165,000 dues-paying members on our roster. We are one of the fastest-growing new organizations in the country, a fact that bespeaks of the deep opposition of the American people to programs that use language to foster social fragmentation and separatism, such as prolonged programs of bilingual/bicultural education.

Since last spring, there have been a number of developments which bear upon bilingual education:

—After thorough review, Secretary of Education William Bennett announced his department's conclusion that transitional bilingual education, which has been tried for 17 years, at a cost of $1,700,000,000 in Federal money, has failed to prove its effectiveness. He urged that the Bilingual Education Act be changed to allow greater methodological flexibility to local school authorities coping with large numbers of pupils who don't know English.

—Though only 4 percent of the appropriations under the Bilingual Education Act can be allocated to programs utilizing alternative learning methods, 25 percent or more of the grant requests have been for programs under that 4 percent cap.

—The Senate, in its fiscal year 1986 Appropriations Committee report, took the unusual step of directing the Secretary of Education to "pursue administrative, regulatory and legislative actions which will improve fluency in English . . . by allowing local schools and parents the flexibility to determine which method of instruction would be most appropriate for their children."

—A poll by the Associated Press and Media General, taken last November, tells us that the American public supports foreign language instruction for American children, but wants students who don't know English taught in an English language environment.

Finally:

—Your constituent mail this past year has reflected an increased public awareness of the need to redirect the educational offerings for immigrant students to emphasize the acquisition of English.

In view of this indisputable public disenchantment, we recommend a funding level for fiscal year 1987 not to exceed $100,000,000. We further recommend that this entire amount be allocated specifically for classroom instruction. At present, only about two-thirds of Title VII appropriations go toward direct teaching of language minority children deemed to be in need of special assistance.

The Bilingual Education Act is a gross legislative anomaly. It is the only piece of education legislation that mandates a specific teaching method. It also establishes, within the Act, a self-perpetuating sinecure for the special interests who profit from bilingual education. The various sections of the Act fund the mechanisms for the permanent entrenchment and expansion of bilingual education as a fixture in American education:

—Title VII monies fund the establishment of separate bilingual education departments in colleges and universities.

—Title VII monies provide financial inducements for students to study this subspecialty.

—Title VII monies provide guaranteed teaching jobs in the schools for these subsidized graduates from the subsidized departments.

—Title VII research monies provide funds for post-baccalaureate bilingual education programs, jobs for graduates of these programs, and control of the research to justify the continuation and growth of a bilingual education monopoly.

We believe that this cradle-to-grave approach is bad public policy. It inextricably links the educational needs of immigrant children to the job security of bilingual education teachers. We have learned, over the last two decades, that these interests often diverge.

There are other sources of assistance for education departments and for college and graduate students, and bilingual education majors should avail themselves of these, rather than have a special reserve specifically set up and maintained for them by the United States Congress.

In proposing an appropriation of $100,000,000 for bilingual education, we urge that all these monies be earmarked for direct classroom services to non-English speaking children. We further propose that $20,000,000 of the monies thus saved be reallocated to adult education programs, under the terms of the Adult Education Act, for the express purpose of increasing the opportunities available to adults to learn English.

We recognize the Federal Government's obligation to help immigrant children by providing special assistance to their schools. However, the Bilingual Education Act, as it stands, is not the instrument for carrying out that obligation.

Let us hope that the day is not far off when this offensive legislation is replaced by other measures that truly have the potential of helping language minority students. At that time, we shall be here, before this same subcommittee, to plead the case for significant funding increases for programs of English acquisition that will help immigrant students to succeed in this society.

Thank you.

Mr. NATCHER. Thank you very much, Ms. Bikales. You made an excellent statement, and we appreciate your appearance before the committee.

MONDAY, MAY 5, 1986.

BILINGUAL EDUCATION

WITNESSES

SARAH E. MELENDEZ, PAST PRESIDENT, NATIONAL ASSOCIATION FOR BILINGUAL EDUCATION, AND ASSOCIATE DIRECTOR, OFFICE OF MINORITY CONCERNS, AMERICAN COUNCIL ON EDUCATION

JAMES J. LYONS, LEGISLATIVE COUNCIL, NATIONAL ASSOCIATION FOR BILINGUAL EDUCATION

Mr. NATCHER. Our next witness is Dr. Sarah Melendez. Come around, Dr. Melendez, Mr. James Lyons, come up have a seat with us.

Ms. MELENDEZ. Thank you, Mr. Chairman. It is a pleasure and an honor to appear before you again to testify on appropriations for Federal bilingual education programs.

Earlier this month, Education Secretary William Bennett sent to Congress his statutory report on the "Condition of Bilingual Education in the Nation, 1986" This report, like other components of the Secretary's so-called "initiative" on bilingual education—including the department's fiscal year 1987 budget request—misrepresents the true condition of bilingual education in the Nation and the needs of American language-minority students.

Four years ago, Education Secretary Terrell Bell reported to Congress that there were approximately 3,600,000 children of school age who were eligible for Title VII programs and services. While the department was serving about 10 percent of the total universe of limited-English-proficient (LEP) students, Secretary Bell stated that "Schools in general are not meeting the needs of LEP children." Indeed, according to the department, "Only about a third of the LEP children aged 5 to 14 . . . are receiving either bilingual instruction . . . or instruction in English as a second language without the use of their home languages."

Two years ago, in his 1984 report on the "Condition of Bilingual Education in the Nation," Secretary Bell updated the department's estimates of the size of the limited-English-proficient population by noting:

"More current, but preliminary information, based on the 1980 Census and the 1982 English Language Proficiency Survey, indicates an increase in the [Non-English-Language Background (NELB) and Limited-English-Proficient (LEP) student] populations."

Now, two years later, Education Secretary Bennett reports to Congress that:

"There are from 1,200,000 to 1,700,000 of these LEP school-aged children (5–17) who are most in need of services under the [Title VII] statute. . . . This estimate is a revision of the Department's earlier estimates. . . ."

At the same time, the Education Department has testified that between 94 and 97 percent of LEP students are receiving special services.

Mr. Chairman, the department's new LEP population and service estimates represent a cynical exercise in voodo demographics.

Virtually all reports indicate continuing substantial growth of our LEP population. This population growth—the product of powerful domestic demographic trends and world forces—presents a major challenge to American education.

The sad fact is that we are not meeting this challenge.

The Education Department and the Office of Management and Budget have devised an elaborate budgetary shell game to mask the administration's indifference to the needs of language-minority students. Secretary Bennett has repeatedly asserted that the administration is seeking increased funding for Title VII programs.

The deparment's Title VII request of $143,000,000 is roughly $4,000,000 over the 1986 appropriation level. This increase, however, is offset many times over by the fiscal year 1987 reductions sought by the administration for other programs serving language-minority students. These proposed funding cuts include:

—Elimination of the $3,000,000-plus vocational training program;

—Elimination of the $30,000,000 immigrant education program;

—A $50,000,000 cut in funding for the Chapter 1 migrant program;

—Elimination of the $24,000,000 training and advisory services program authorized under Title IV of the Civil Rights Act of 1964;

—Elimination of the Follow Through program and the high school equivalence program for migrants; and,

—Multi-million-dollar cuts tied to restructuring of other educational programs including Indian education, talent search, Upward Bound, and the college assistance migrant program.

While I recognize that this is not the proper forum to debate the Secretary's legislative proposals to increase the "flexibility" of the bilingual education program, the administration's request that this subcommittee adopt legislative language setting aside the internal funding formulas specified in Public Law 98-0511 necessitates two observations.

First, the internal Title VII funding formulas set out in Public Law 98-511 represent Congress' most recent and best judgment as to how the Federal Government's limited resources can best serve LEP students and the schools where they are enrolled.

Second, the existing statutory escalator provision offers the Secretary an immediate mechanism for accomplishing his proclaimed objective. Because the department's request falls short of the $144,000,000 level, however, it does not set in motion the funding escalator which would dramatically boost spending for the Secretary's favorite Title VII program.

We also call upon you to reject the administration's proposed legislative language. We also call upon the subcommittee to increase funding for the Title VII program. According to the Legislative Reference Service, Title VII services have been reduced by almost 50 percent since 1980 because of funding cuts and inflation.

Finally, I call to your attention a number of issues which warrant the subcommittee's attention as possible subjects of legislative or report language.

First, the department will soon publish new final program regulations to implement the revised Bilingual Education Act. Some months ago, the department published for public comment a set of draft regulations. The draft regulation were criticized by numerous national organizations concerned with the effective education of LEP students and by Democratic and Republican Members of the House and Senate authorizing committees. If the final Title VII regulations are not revised so as to accord with the letter and spirit of Public Law 98-511, we ask that you consider including in your funding bill appropriate legislative restrictions and guidance.

Second, despite a direct request from Chairman Hawkins, the Education Department has failed to release a number of studies and evaluations which were conducted with Title VII monies. We understand that the first year findings contradict the Secretary's assertions regarding the effectiveness of immersion programs—his preferred type of program. We hope that your subcommittee can facilitate the release of all Title VII-funded studies and reports.

Third, the department proposes to reduce funding for Title VII graduate training on the grounds that "few of the fellows complete their degrees and actually provide classroom instruction." This is simply untrue. My full statement gives more information.

According to the Title VII-funded "Study of Teacher Training Programs in Bilingual Education," most of the students receiving masters or doctorates in bilingual/ESL education graduated from Title VII supported training programs. And according to the same report, "86 percent of the trainer graduates were employed in bilingual education positions."

We hope the subcommittee will scrutinize this situation closely, and will take whatever steps are necessary to ensure the uninterrupted flow of clearinghouse services at a level comparable to that provided under previous appropriations.

Fifth, information transmitted by the Education Department to Congress followed a request by the three House subcommittee chairmen who share oversight responsibility for the activities of the department's Office for Civil Rights (OCR) indicates a marked decrease in OCR's efforts to ensure compliance with the requirements of Title VI of the Civil Rights Act and the United States Supreme Court's landmark ruling in Lau v. Nichols.

We ask that your subcommittee consider directives which would prevent OCR from reducing further its Title VI Lau enforcement program.

Sixth, and finally, we call to your attention to the irresponsible and reprehensible public statements of members of the National Advisory and Coordinating Council on Bilingual Education (NACCBE). In one press report, the chairman of the NACCBE stated that "Bilingual education is part of a silent conspiracy to keep Spanish-speaking children in linguistic bondage." Such public statements—and we can provide the subcommittee with many other examples—coupled with the shallowness and bias evident in NACCBE's most recent published report, call into question NACCBE's utility as an advisory and coordinating body. Indeed, the subcommittee may find that the NACCBE, as currently constituted, is not deserving of continued financial support.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much, Dr. Melendez. We appreciate your appearance. You have given us a good statement.

[The statement of Ms. Melendez follows:]

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15th ANNUAL INTERNATIONAL
BILINGUAL-BICULTURAL
EDUCATION CONFERENCE
PALMER HOUSE HOTEL
CHICAGO, ILLINOIS
APRIL 1-5, 1986
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TESTIMONY

OF

THE NATIONAL ASSOCIATION FOR BILINGUAL EDUCATION

ON FY 1987 FUNDING FOR BILINGUAL EDUCATION

PRESENTED BY

DR. SARAH E. MELÉNDEZ
NABE PAST PRESIDENT AND ASSOCIATE DIRECTOR,
OFFICE OF MINORITY CONCERNS, AMERICAN COUNCIL ON EDUCATION

ACCOMPANIED BY

MR. JAMES J. LYONS, NABE LEGISLATIVE COUNSEL

TO

THE HOUSE APPROPRIATIONS SUBCOMMITTEE

ON LABOR - HEALTH AND HUMAN SERVICES - EDUCATION

APRIL 23, 1986

Mr. Chairman, it's a pleasure and an honor to appear before you again to testify on appropriations for Federal bilingual education programs. With me today is NABE's Legislative Counsel, Jim Lyons.

Earlier this month, Education Secretary William Bennett sent to Congress his statutory report on the "Condition of Bilingual Education In the Nation, 1986." This report, like other components of the Secretary's so-called "initiative" on bilingual education -- including the Department's FY 1987 budget request -- misrepresents the true condition of bilingual education in the Nation and the needs of American language-minority students.

Voodo Demographics

Four years ago, Education Secretary Terrell Bell reported to Congress that there were approximately 3.6 million children of school age who were eligible for Title VII programs and services. While the Department was serving about 10 percent of the total universe of limited-English-proficient (LEP) students, Secretary Bell stated that "schools in general are not meeting the needs of LEP children." Indeed, according to the Department, "only about a third of the [LEP] children aged 5 to 14 ... are receiving either bilingual instruction ... or instruction in English as a second language without the use of their home languages."

Two years ago, in his 1984 report on the "Condition of Bilingual Education in the Nation," Secretary Bell updated the Department's estimates of the size of the limited-English-proficient population by noting:

> More current, but preliminary information, based on the 1980 Census and the 1982 English Language Proficiency Survey, indicates an increase in the [Non-English-Language Background (NELB) and Limited-English-Proficient (LEP) student] populations.

Now, two years later, Education Secretary Bennett reports to Congress that

> There are from 1.2 to 1.7 million of these [LEP] school-aged children (5-17) who are most in need of services under the [Title VII] statute. ... This estimate is a revision of the Department's earlier estimates....

At the same time, the Education Department has testified that between 94 and 97 percent of LEP students are receiving special services.

Mr. Chairman, the Department's new LEP population and service estimates represent a cynical exercise in voodo demographics.

Virtually all reports indicate continuing substantial growth of our LEP population. This population growth -- the product of powerful domestic demographic trends and world forces -- presents a major challenge to American education.

The sad fact is that we are not meeting this challenge. Formal studies and informal reports show that most LEP students are not being adequately served, they are not being effectively educated. In New York City alone, according to the report of the Education Priorities Panel, more than 45,000 LEP students are receiving no special services to overcome the language barriers which impede successful learning.

What's At Stake and What It Takes

The educational success of American language-minority students is critical to the nation's well-being. We cannot afford -- economically, politically, or socially -- to permit millions of students to pass through or drop out of our schools without mastering the English language and the other subjects taught in our country's classrooms.

The educational needs of LEP students will not be met through callous statistical manipulations; nor will they be met by artificially lowering educational standards and expectations. The effective schooling of LEP students requires human and financial resources -- resources which are in short supply.

Budget Shell Game

The Education Department and the Office of Management and Budget have devised an elaborate budgetary shell game to mask the Administration's indifference to the needs of language-minority students. Secretary Bennett has repeatedly asserted that the Administration is seeking increased funding for Title VII programs.

Indeed, the Department's Title VII request of $143 million is roughly $4 million over the 1986 appropriation level. This increase, however, is offset many times over by the FY 1987 reductions sought by the Administration for other programs serving language-minority students. These proposed funding cuts include:

- o Elimination of the $3+ million Vocational Training program;
- o Elimination of the $30 million Immigrant Education program;
- o A $50 million cut in funding for the Chapter 1 migrant program;
- o Elimination of the $24 million Training and Advisory Services program authorized under Title IV of the Civil Rights Act of 1964;

- o Elimination of the Follow Through program and the High School Equivalence Program for migrants; and,

- o Multi-million dollar cuts tied to restructuring of other educational programs including Indian Education, Talent Search, Upward Bound, and the College Assistance Migrant Program.

The Bogus Issue of "Flexibility"

I recognize that this is not the proper forum to debate the Secretary's legislative proposals to increase the "flexibility" of the bilingual education program. Such a debate would be more appropriate before the authorizing committee. Nevertheless, the Administration's request that this subcommittee adopt legislative language setting aside the internal funding formulas specified in Public Law 98-511 necessitates two observations.

First, the internal Title VII funding formulas set out in Public Law 98-511 represent Congress' most recent and best judgment as to how the Federal government's limited resources can best serve LEP students and the schools where they are enrolled. These formulas were thoughtfully and painstakingly developed by a bi-partisan group of members of the House authorizing committee; and they were ratified by a bi-partisan majority in both the House and the Senate.

Second, the existing statutory escalator provision which sets aside 50 percent of all Title VII appropriations in excess of $144 million for the Special Alternative Instruction Program (to a maximum of 10 percent of total Title VII funding) offers the Secretary an immediate mechanism for accomplishing his proclaimed objective. Because the Department's request falls short of the $144 million level, however, it does not set in motion the funding escalator which would dramatically boost spending for the Secretary's favorite Title VII program.

Accordingly, we call upon you to reject the Administration's proposed legislative language. We also call upon the subcommittee to increase funding for the Title VII program. According to the Legislative Reference Service, Title VII services have been reduced by almost 50 percent since 1980 because of funding cuts and inflation. A restoration of Title VII funding to 1980 service levels represents a realistic response to Secretary Bennett's so-called "initiative" on bilingual education.

Ensuring Proper Expenditure of Appropriations

Finally, I call to your attention a number of issues which warrant the subcommittee's attention as possible subjects of legislative or report language. Many of these issues are currently being studied by the House Education and Labor Committee, and I trust that you will confer with Chairman Hawkins prior to your subcommittee mark-up.

First, the Department will soon publish new final program regulations to implement the revised Bilingual Education Act. Some months ago, the Department published for public comment a set of draft regulations. The draft regulations were criticized by numerous national organizations concerned with the effective education of LEP students and by Democratic and Republican members of the House and Senate authorizing committees. If the final Title VII regulations are not revised so as to accord with the letter and spirit of Public Law 98-511, we ask that you consider including in your funding bill appropriate legislative restrictions and guidance.

Second, despite a direct request from Chairman Hawkins, the Education Department has failed to release a large number of studies and evaluations which were conducted with Title VII monies. One of the reports which has not been released provides the first year results of a comparative study of so-called immersion programs versus two types of bilingual programs. We understand that the first year findings contradict the Secretary's assertions regarding the effectiveness of immersion programs. We hope that your subcommittee can facilitate the release of all Title VII-funded studies and reports.

Third, the Department proposes to reduce funding for Title VII graduate training on the grounds that "few of the fellows complete their degrees and actually provide classroom instruction." This is simply untrue. According to the Title VII-funded "Study of Techer Training Programs in Bilingual Education", most of the students receiving masters or doctorates in bilingual/ESL education graduated from Title VII supported training programs. And according to the same report, "86 percent of the trainer graduates were employed in bilingual education positions."

Fourth, there is accumulating evidence that the National Clearinghouse on Bilingual Education is being dismantled. The Clearinghouse is one of the most effective components of the Title VII program. During the last 5 years, the Clearinghouse has responded to an annual average of over 15,000 requests from teachers, administrators, and parents for information on bilingual, ESL, and other programs specially designed to meet the academic needs of language-minority students.

Sometime ago, the Department decided to recompete the contract for the Clearinghouse. The competition process bogged down, and a non-competitive 6-month extension was awarded to the original contractor. The extension, however, specified a decreased level of activity and narrowed scope-of-effort.

During the non-competitive extension, the Department published a RFP for the new Clearinghouse competition. This RFP projects further reductions in the level of Clearinghouse activities and effort.

The Department failed to carry out the Clearinghouse recompetition during the course of the 6-month non-competitive extension. Instead of extending the existing contract until a new competitive award is made, the Education Department entered into a sole-source 3-month "interim" contract with a new firm thereby occasioning a disruption of Clearinghouse service.

We hope the subcommittee will scrutinize this situation closely, and will take whatever steps are necessary to ensure the uninterrupted flow of Clearinghouse services at a level comparable to that provided under previous appropriations.

Fifth, information transmitted by the Education Department to Congress following a request by the three House subcommittee chairmen who share oversight responsibility for the activities of the Department's Office for Civil Rights (OCR) indicates a marked decrease in OCR's efforts to ensure compliance with the requirements of Title VI of the Civil Rights Act and the United States Supreme Court's landmark ruling in Lau v. Nichols. While congressional action to remedy an apparent weakening of civil rights compliance standards is best left to the subcommitees with substantive jurisdiction, we ask that your subcommittee consider directives which would prevent OCR from reducing further its Title VI Lau enforcement program.

Sixth, and finally, we call to your attention the irresponsible and reprehensible public statements of members of the National Advisory and Coordinating Council on Bilingual Education (NACCBE). In one press report, the Chairman of the NACCBE stated that "bilingual education is part of a silent conspiracy to keep Spanish-speaking children in linguistic bondage." Such public statements -- and we can provide the subcommittee with many other examples -- coupled with the shallowness and bias evident in NACCBE's most recent published report, call into question NACCBE's utility as an advisory and coordinating body. Indeed, the subcommittee may find that the NACCBE, as currently constituted, is not deserving of continued financial support.

MONDAY, MAY 5, 1986.

PEACE INSTITUTE

WITNESS

ROBERT J. CONLAN, EXECUTIVE DIRECTOR, NATIONAL PEACE INSTITUTE FOUNDATION

Mr. **NATCHER**. Our next witness is Mr. Robert Conlan. We are glad to have you with us.

Mr. **CONLAN**. Thank you very much, Mr. Chairman. To stay within the five minutes, I will read highlights from the written testimony.

Mr. **NATCHER**. That will be fine.

Mr. **CONLAN**. Thank you, Mr. Chairman, and Mr. Conte.

My name is Robert J. Conlan. I am the Executive Director of the National Peace Institute Foundation. The foundation is the successor organization to the 45,000-member National Peace Academy Campaign which worked with Members of Congress for 10 years to create the United States Institute of Peace.

I think it almost goes without saying that conflict and its peaceful resolution is the dominant—the crucial—challenge of our times and perhaps all times. I don't know quite how I can emphasize that enough . . . how I can say it as forcefully as I believe it must be said.

But it is a simple fact that if we do not learn to handle conflict far better than the human race has ever handled conflict in the past, then we and our civilization, the product of thousands of years of humankind's beset efforts, shall not survive.

Perhaps that says it all.

In 1984 Congress established the United States Institute of Peace (USPI)—the first government body ever created in our country whose express purpose it is to enhance America's national security by using conflict resolution techniques in international conflict management, instead of relying solely on a show of force . . . or confrontation . . . or even warfare itself.

As you know, there was a long delay in naming the Board of Directors, but USIP's Board of Directors has now been formed. Its president has been hired. Other staff soon will be hired and program priorities will be set. That's the good news.

The bad news is that the board is narrowly based—lacking women, minorities, business people, labor leaders, and the like. However, I feel certain that working together over time we can broaden the board's makeup.

But for right now . . . these critically important questions about the USIP's future remain: Will it take hold? Will it do what it was established to do? Will the USIP grow into the force it must become in order to change the way the world resolves conflicts? The answers to these questions really depend on you in Congress.

In government today, professional training in negotiation and mediation is lost among a welter of Federal institutions dominated either by day-to-day events or military concerns. What is everybody's business has become nobody's business. But you and the United States Institute of Peace can change all that.

The Peace Institute can become the central active government body which will focus attention, stimulate thinking, and conduct meaningful exercises in conflict resolution.

But, to be successful the Peace Institute must be kept free of partisan politics. It must he kept free of overbearing influence from America's diplomatic and military establishment.

And, working together, I'm convinced that we can keep the Peace Institute above politics, and above all manner of pressure brought by those who oppose its very being.

But the work must begin immediately. If ever there was a need for an effective, responsible national institution devoted to teaching and research in how to create the conditions for peace, it is now. There are approximately 135 ongoing conflict around the world. And no one can tell which of these might erupt into a major global catastrophe.

Through your past support, the Members of this committee have directly endorsed and made possible the idea of international conflict resolution—and its potential for avoiding nuclear war and maintaining peace.

And now, after a decade of struggling and painstaking effort to bring an idea of the highest moral value to fruition, the Peace Institute is a reality. This truly remarkable new organization is a breakthrough in the field of peacemaking. It deserves to succeed—and deserves your continued support to help insure its success.

I think you will agree that our Nation has allowed a terrible gap to develop between the application of science to war and its application to the cause of peace. The Peace Institute can begin closing that terrible gap. This committee must see to that.

And perhaps even more important, the Peace Institute can serve as a symbol—a symbol that history's most powerful Nation is committed to a long-term program of research and training and education in the ways and means of peace.

Two thousand years ago the Romans said, "Si pacem vis, bellum para"—"If you wish for peace, prepare for war."

What a remarkable accomplishment it would be to leave as a legacy to future generations a new dictum—an American dictum: "Si pacem vis, pacem para"—"If you wish for peace, prepare for peace."

Last week the chairman and president of the United States Institute of Peace testified that there is still no consensus among the board of directors of the Institute on the size of its 1987 budget.

The Institute has, in fact, rather unenthusiastically submitted the administration's totally inadequate request for $1.250,000 in additional funding for fiscal year 1987.

Perhaps it is too early in the Institute's life to expect the independence that Congress has in mind when it designed the Institute as an independent institution directly accountable to Congress.

But this should not deter you. For 10 years Congress has become increasingly committed to an independent body dedicated to peacemaking.

This committee last year sent a clear signal to the administration when it refused to go along with the recession of the $4,000,000 that Congress appropriated for the Peace Institute for fiscal year 1985.

That, coupled with Congressional refusal to even consider the crippling amendments to the Peace Institute charter introduced by the State Department, got the administration moving on naming the Peace Institute's board of directors.

Perhaps it is time for the Congress to send a message to the board of directors of the Institute about how serious Congress is about this project.

Along with my testimony, the Foundation is submitting a budget justification for $8 million for fiscal year 1987. This would include $2,000,000 rolled over in the Institute Endowment from the fiscal year 1985 appropriation plus $6,000,000 in new appropriations.

This budget would send a signal to the board of directors that Congress is fully committed to building a world-class Peace Institute.

In addition, I would like to submit a copy of a questionnaire, the results of such, that we distributed to our members of the National Peace Institute Foundation, and there are 4,117 responses, and it shows what the priorities that our members think the Peace Institute should be looking at.

Thank you very much, Mr. Chairman.

Mr. NATCHER. Mr. Conlan, thank you for your appearance. You have given an excellent statement, Mr. Conlan, and we thank you very much.

[The statement of Mr. Conlan follows:]

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Chairman of the Board

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Executive Director

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Former Member of Congress
The Honorable Maurine Neuberger
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Paul Newman
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The Honorable Jennings Randolph
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Vice Admiral Ralph Weymouth
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Herman Will
United Methodist Church
Colin W. Williams
Aspen Institute
The Honorable Andrew Young
Mayor, Atlanta, Georgia

STATEMENT OF

ROBERT J. CONLAN

EXECUTIVE DIRECTOR

OF THE

NATIONAL PEACE INSTITUTE FOUNDATION

BEFORE THE

SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES, EDUCATION,

AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

MAY 5, 1986

BOARD OF DIRECTORS: Elise Boulding • John P. Dunfey • Rev. George W. Hill • Harry J. Hogan • James H. Laue • John G. Moore • Mary Purcell • Nancy Ramsey • Libby Rouse · Charles E. Smith • William Spencer • David Straus • Thomas C. Westropp • Vice Admiral Ralph Weymouth

NATIONAL PEACE INSTITUTE FOUNDATION

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Executive Director
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STATEMENT OF
ROBERT J. CONLAN
EXECUTIVE DIRECTOR
OF THE
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This Committee last year sent a clear signal to the Administration when it refused to go along with the recession of the $4 million that Congress appropriated for the Peace Institute for FY85.

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This budget would send a signal to the Board of Directors that Congress is fully committed to building a world class Peace Institute.

This budget

- ensures that the Institute will not be just another Washington-based think-tank, but a national educational institution -- providing for "in-house" programs, affiliate relations with other institutions and grants to other institutions (at a rate of one per state);

- emphasizes the three functions of the Institute: research ($1,860,000), education/training ($3,485,000) and information distribution ($1,720,000);
- provides that 78% of the annual budget be spent directly on program;
- provides twice as much money for grants as required by statute (assuming an additional $4 million appropriation for FY87); and
- provides almost twice as much money for programs at other institutions as it spends on its own programs.

Annex A

PROJECTED FY87 OBLIGATIONS OF THE UNITED STATES INSTITUTE OF PEACE

(1) Board of Directors

daily pay	15 Directors x $ 260/day x 2 days/month	=	$ 93,600
per diem	15 Directors x $ 75/day x 2 days/month	=	27,000
travel	15 Directors x $ 120/mtg x 1 mtg/month	=	21,600
			$ 142,200

(2) Facilities

principal office		
40 employees x 200 sq. ft./pers. x $ 30/sq. ft.	=	$ 240,000
information access offices		
20 employees x 200 sq. ft./pers. x $ 30/sq. ft.	=	120,000
		$ 360,000

(3) General Administration

personnel				
administration	10 x	$ 35,000	=	$ 350,000
research/development	15 x	(see below)		
education/training	10 x	(see below)		
program support	5 x	28,000	=	140,000
public infor. serv.	20 x	35,000	=	700,000
office				
travel			=	16,000
office machines/computer serv.			=	40,000
supplies/equipment/misc.			=	60,000
				$ 1,306,000

(4) "In-House" Programs

research projects	10 x	$ 60,000	=	$ 600,000
develop educ. prog./ref. mat.	5 x	75,000	=	375,000
education	5 x	36,000	=	180,000
training	5 x	36,000	=	180,000
publications			=	400,000
clearinghouse			=	500,000
				$ 2,235,000

(5) Grantmaking Programs

Jennings Randolph Fellowships	10 x	$ 36,000	=	$ 360,000
grants to institutions				
basic research	15 x	60,000	=	900,000
educational programs				
instr. for sec./elem. schls.	10 x	130,000	=	1,300,000
conferences/workshops	5 x	100,000	=	500,000
discipline development	10 x	95,000	=	950,000
				$ 4,010,000

$ 8,053,200

JUSTIFICATION OF PROJECTED FY87 OBLIGATIONS OF THE UNITED STATES INSTITUTE OF PEACE

(1) Board of Directors

P.L. 98-525, Sec. 1706(i) and (j) provide that nonstatutory Board members "receive the daily equivalent of the annual rate of basic pay in effect for grade GS-18 ... for each day during which the director is engaged in the performance of duties as a member of the Board." Also, directors are allowed travel expenses and a per diem while away from home or regular place of business in the performance of duties as a member of the Board.

According to a Pay and Benefits Specialist at the Office of Personnel Management, the daily equivalent for grade GS-18 is $263.36. According to the General Services Administration, the per diem for nearly 200 high cost cities in the U.S. is fixed at $75. The projected travel expenses represent a reasonable estimate of cost for a geographically diverse Board of Directors.

(2) Facilities

The Deputy Director for Real Estate in the National Capital Region of the General Service Administration reported that it is customery to allocate 200 sq. ft./person, and that a full service lease for office space--not the best or worst in town--would cost about $30/sq. ft.

The same numbers were used to estimate the cost of regional information access offices for 3 staff in Atlanta, Boston, Chicago, Dallas and San Francisco, and for 5 staff in New York City.

(3) General Administration

Sec. 1707(a) stipulates that the Institute's president and other officers shall be paid at rates not to exceed level I of the Executive schedule ($86,200 annually). The pay of other employees shall be governed by provisions in the United States Code relating to General Schedule pay rates.

Salary estimates and number of Institute employees are taken from the pay rates used and number of people employed by the Woodrow Wilson International Center for Scholars. At the Wilson Center, the average annual salary for administrative functions is $35,000 (x 12 employees), for public service is $44,000 (x 14 employees) and for scholar support is $28,000 (x 7 employees). Office expenses for travel, office machines, computer services, supplies, equipment and miscellaneous services, are taken directly from the Wilson Center.

It is reasonable to project for the Institute an administrative staff of 10 to oversee its three functions (research, education and training, and information distribution), and a program staff of 5 to direct its three principal modes of operation (in-house programs, programs in cooperation with other institutions, and grantmaking programs).

The public information/service positions are designed to staff six regional information access offices. The salary estimate for these positions is based on the Wilson Center's administration salaries rather than its public service salaries because it is unlikely that all 20 positions would require professionals.

The costs projected for the Institute's research projects and activities to develop educational programs and basic reference materials are based on the actual average grant paid by the National Endowment for the Humanities for similar work.

The projected salaries for education and training are based on the Wilson Center's policy of providing a stipend at the GS-13/1 rate ($36,327) for its fellows. It is assumed that this is a fair market rate for serious academic work.

The projected publication costs for the Institute are taken from the costs of publication for the Foreign Service Institute. The cost of contracting out for clearinghouse services is based on estimates from the budget office at the National Institute of Corrections regarding its information clearinghouse in Colorado: its average annual cost is approximately $600,000 for staff, facilities, equipment, and the reproduction and distribution of documents.

(5) Grantmaking Programs

The Jennings Randolph Program for International Peace is authorized to provide grants, fellowships and stipends to scholars and leaders for the purpose of research. The cost of the fellowships is based on the GS-13/1 rate ($36,327) paid by the Wilson Center to its fellows.

The Institute is mandated to pay at least one-fourth of its annual appropriation to nonprofit or official public institutions. Such grants will probably be paid for basic research or the creation of educational and training programs. The amounts for such grants are taken directly from the average grant paid for similar purposes by the National Endowment for the Humanities.

(6) Overview of the draft budget

- ensures that the Institute will not be just another Washington-based think-tank, but a national educational institution--providing for "in-house" programs, affiliate relations with other institutions and grants to other institutions (at a rate of one per state);

- emphasizes the three functions of the Institute: research ($1,860,000), education/training ($3,485,000) and information distribution ($1,720,000);

- provides that 78% of the annual budget be spent directly on program;

- provides twice as much money for grants as required by statute (assuming an additional $4 million appropriation for FY86); and

- provides almost twice as much money for programs at other institutions as it spends on its own programs.

Annex B

Biography of Witness

ROBERT J. CONLAN
EXECUTIVE DIRECTOR
NATIONAL PEACE INSTITUTE FOUNDATION

Robert J. Conlan is the Executive Director of the National Peace Institute Foundation and is responsible for day-to-day operations and long-range planning. From 1979 to 1983, Mr. Conlan was Legislative Liaison Officer for the National Cooperative Bank. He was the Executive Director of the Cooperative Bank Action National Committee which worked to create the Cooperative Bank before coming to Washington in 1979. Mr. Conlan was also Assistant to New York City Mayor John Lindsay and Chief of Staff for a member of Congress.

MEMBERSHIP QUESTIONNAIRE February 13, 1986
4117 RESPONSES

Crucial decisions about the United States Institute of Peace will be made soon. We want members of the Foundation to give advice on these decisions. Limited resources dictate that we make important choices about our own program. We need your help. Please take just a minute to fill out the questionnaire so that we can better plan for the future.

MEMBERS' OPINIONS

PLEASE RATE IN IMPORTANCE FROM FIVE (TOP PRIORITY) TO ONE (LOW PRIORITY).

I. The United States Institute of Peace will concentrate on three main areas:

- o Education and Training
- o Research
- o Information Dissemination and Public Outreach

Please give us the priority you would give to each.

	High 5	4	Medium 3	2	Low 1	N\A
Education and Training	2690 65%	920 22%	360 9%	50 1%	17 0%	80 2%
Research	1231 30%	1151 28%	1290 31%	206 5%	114 3%	125 3%
Information Dissemination and Public Outreach	2107 51%	963 23%	780 19%	112 3%	54 1%	101 2%

II. In the area of Education and Training, what importance would you give to different population groups? (Elementary and Secondary School Levels, College Level, Adult Education, Programs for Public Officials).

	High 5	4	Medium 3	2	Low 1	N\A
Elementary and Secondary School Levels	1702 41%	759 18%	922 22%	445 11%	150 4%	139 3%
College Level	1879 46%	1305 32%	701 17%	104 3%	43 1%	85 2%
Adult Education	1376 33%	1353 33%	950 23%	246 6%	70 2%	122 3%
Programs for Public Officials	2660 65%	708 17%	396 10%	200 5%	64 2%	89 2%

III. In the area of Research, what importance would you give to various approaches? (Global Issues in Common to All Nations, Improving Peacemaking Techniques, Areas of Potential International Cooperation, Characteristics of a Peaceful World, Facilitation of Our Nation's Transition to a Peaceful Economy).

	High 5	4	Medium 3	2	Low 1	N\A
Global Issues in Common to All Nations	1530 37%	1165 28%	849 21%	263 6%	105 3%	205 5%
Improving Peacemaking Techniques (Negotiation, Mediation and Conciliation)	2883 70%	671 16%	301 7%	82 2%	48 1%	132 3%
Areas of Potential International Cooperation	1605 39%	1405 34%	731 18%	152 4%	38 1%	186 5%
Characteristics of a Peaceful World	781 19%	890 22%	1233 30%	550 13%	389 9%	274 7%
Facilitation of Our Nation's Transition to a Peaceful Economy	1865 45%	928 23%	675 16%	302 7%	204 5%	143 3%

IV. With regard to the content of Educational and Training Programs, what importance would you give to various aspects of the peace process? (The Concept of Peace, Causes of Conflict, Methods of Conflict Resolution, Current Conflicts).

	High 5	4	Medium 3	2	Low 1	N\A
The Concept of Peace	1256 31%	1036 25%	1000 24%	412 10%	123 3%	290 7%
Causes of Conflict	1873 45%	1298 32%	604 15%	102 2%	34 1%	206 5%
Methods of Conflict Resolution	3233 79%	552 13%	189 5%	25 1%	12 0%	106 3%
Current Conflicts	928 23%	1315 32%	1110 27%	399 10%	97 2%	268 7%

Mr. Natcher. The committee will now adjourn until 11 o'clock in the morning.

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